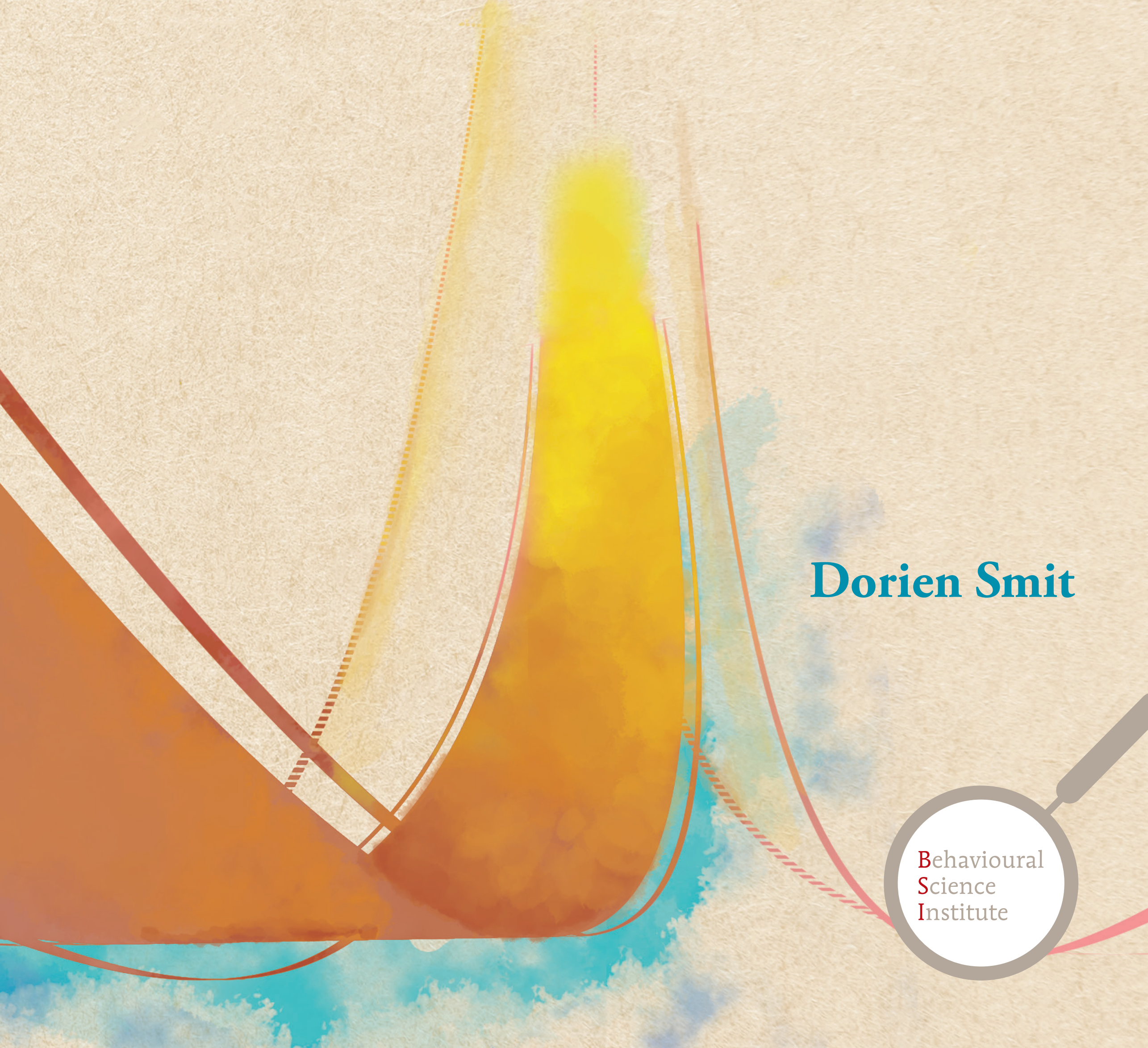
Experiential knowledge and peer support for recovery in depression

Dorien Smit



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Dorien Agnes Smit
geboren op 18 augustus 1987
te Breda

Promotor:
Prof. dr. J. Spijker

Copromotoren:
Dr. B.F. Groeneweg (Depressie Vereniging)
Dr. J.N. Vrijsen

Manuscriptcommissie:
Prof. dr. G.J.M. Hutschemaekers
Prof. dr. A.E.M. Speckens
Prof. dr. S. Castelein (Rijksuniversiteit Groningen)

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by

Dorien Agnes Smit
born on August 18, 1987
in Breda (the Netherlands)

Supervisor:
Prof. dr. J. Spijker

Co-supervisors:
Dr. B.F. Groeneweg (Depressie Vereniging)
Dr. J.N. Vrijsen

Manuscript Committee:
Prof. dr. G.J.M. Hutschemaekers
Prof. dr. A.E.M. Speckens
Prof. dr. S. Castelein (University of Groningen)

Table of Contents

CHAPTER 1

General Introduction

Depression is considered a highly heterogeneous mental disorder (Fried, 2017; Herrman et al., 2022) with symptoms of sadness, insomnia, fatigue and concentration problems (American Psychiatric Association, 2013). Individuals with depression have vastly different experiences, though they universally bring suffering to individual and family lives, impairing social and societal functioning (Lund et al., 2018). Even more important, depression is associated with increased mortality (Cuijpers & Smit, 2002).

It is estimated that around 280 to 320 million individuals are coping with depression worldwide (Üstün, Ayuso-Mateos, Chatterji, Mathers, & Murray, 2004; Vos et al., 2020; WHO, 2017), with an estimated lifetime prevalence of 10% in the general population (Kessing, 2007; Kessler & Bromet, 2013). There are evidence-based treatment options, including psychopharmacology and psychotherapy (Cuijpers et al., 2020). The latter is increasingly and effectively delivered over the internet (e.g., internet-based Cognitive Behavioral Therapy [iCBT]) (Andersson, Titov, Dear, Rozental, & Carlbring, 2019). However, more than 50% of patients experience insufficient improvement of treatment (Rush et al., 2006), and recurrence rates are high. Up to 40% of individuals with depression experience a relapse after four years post-treatment (Steinert, Hofmann, Kruse, & Leichsenring, 2014), and almost 20% of patients develop a chronic depression (characterised by symptoms that last for two or more years) (Gilmer et al., 2005; Penninx et al., 2011). Due to this chronic nature and significant burden, there is a need to know how to cope with persistent or recurring symptoms, instead of focusing on symptom reduction only.

Recovery-Oriented Mental Health Care

In the 1970s the so-called "Consumer Movement", consisting of psychiatric ex-patients, criticized the view of the mental health system with its emphasis on pathology, deficits and dependency. This call for destigmatization of individuals with mental illness compelled a new interpretation of recovery (Frese & Davis, 1997). Recovery should be viewed as a pathway, indicating that there is no final destination but assuming that it is an ongoing journey not limited to the remission of mental health symptoms (Anthony, 1993), which is referred to as *clinical recovery* (Slade et al., 2014; Van Eck, Burger, Vellinga, Schirmbeck, & de Haan, 2018).

Rather, recovery needs an holistic approach, including physical, mental, and social factors and needs of a particular individual (Bonney & Stickley, 2008; Jacob, 2015). The most frequently cited definition of recovery is from Anthony (1993): "a deeply 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" (Anthony, 1993, p. 527). This interpretation for recovery seems to refer primarily to *personal recovery*, as a second domain for recovery in mental illness. To define central aspects for this concept, Leamy and colleagues (2011) systematically reviewed studies for (serious) mental illness for personal recovery. This resulted in the CHIME framework, an acronym for dominant themes in the pathway to personal recovery for mental illness: Connectedness; Hope and optimism about the future; Identity; Meaning in life; and Empowerment (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011).

In addition to clinical and personal recovery, a third recovery domain has recently gained more attention in mental health practice and research: *functional recovery*. This refers to the degree of vocational and social functioning, such as acting according to age-appropriate role expectations, work and study, the performance of daily living tasks without supervision, engagement in social interactions (Robinson, Woerner, McMeniman, Mendelowitz, & Bilder, 2004), and the degree of independence with regard to housing and self-care (Harvey & Bellack, 2009; Swildens et al., 2018; Whitley & Drake, 2010). The three types of clinical, personal, and functional recovery can be seen as complementary rather than distinct and independent processes. Together with its open-ended character, recovery is a complex and multidimensional concept (Bellack, 2006; Jääskeläinen et al., 2013; Whitley & Drake, 2010).

Recovery-Oriented Services in Clinical Practice

Nowadays, the recovery approach in mental health is acknowledged worldwide (Ellison, Belanger, Niles, Evans, & Bauer, 2018). Also the Dutch government emphasize that individuals with mental illness should be supported in multiple life domains to promote recovery (Bestuurlijk Akkoord Geestelijke Gezondheidszorg [GGZ]; GGZ-akkoord, 2018). In mental health care, the recovery approach is reflected by incorporating methods to enhance patient's self-management (GGZ-standaarden, 2019) and the deployment of experiential expertise (e.g., peer support workers) (Boertien & van Bakel, 2012). For patients with chronic or severe conditions or Serious Mental Illness (SMI), recovery-oriented services such as the Wellness Recovery Action Plan (WRAP; Canacott, Moghaddam, & Tickle, 2019) or Flexible Assertive Community Management (FACT; Van Veldhuizen & Bähler, 2013) are widely used to guide the patient towards taking control of their life, living to their goals, needs, and abilities. Additionally, many recovery-oriented services are focused on prevention or sub-threshold depression or mental illness. Example are "Master your Mood" (i.e., "Grip op je Dip"; Gerrits, van der Zanden, Visscher, & Conijn, 2007) or the "Mindfulness coach app", provided by a Dutch health insurance company (van Emmerik, Berings, & Lancee, 2018). Recovery-oriented services for patients with moderate symptoms seem scarce.

Particularly for depression with its chronic nature, the use of recovery-oriented services is advised in international guidelines for mental health care (WHO; Word Health Organisation, 2021; APA; American Psychological Association, 2019; NICE, National Institute for Health and Care Excellence; 2018), and Dutch professional guidelines for depression (Nederlands Huisartsen Genootschap [NHG] and GGZ-standaarden; Spijker et al., 2022; Van Gelderen, Grundmeijer, Licht-Strunk, Van Marwijk, & Van Rijswijk, 2012). These include for example the support of experiential experts (e.g., engaging in initiatives of a patient association), and the use of community-based interventions (including social systems to improve social support). However, the implementation of recovery-oriented services in clinical practice is challenging due to the complex and multidimensional nature of recovery (Slade et al., 2014). Practitioners long for a clear concept for recovery in practice, to shift their focus from organizational goals to the need of the individual patient (Le Boutillier et al., 2015). However, little is known about what individuals with depression experience in their recovery pathway and consider useful when engaging in such recovery programs. Hence, it is difficult to adapt the multiple, widely varying recovery-oriented interventions to the preferences of the individual patient (Slade, 2009). The Lancet-World Psychiatry Association Commission recently called for "united action" to improve supportive systems for recovery in depression. In addition to engaging health care practitioners, policy makers and researchers, including the general community, consisting of individuals with lived experience of depression, is strongly recommended for future research (Herrman et al., 2022).

Experiential Knowledge, a Unique Though Universal Concept?

With its roots in the "Consumer Movement", experiential knowledge is increasingly considered a potential valuable knowledge base for mental health care (Kortteisto, Laitila, & Pitkänen, 2018), recovery-oriented services (Boevink, 2012), and depression specifically (van Grieken, Kirkenier, Koeter, Nabitz, & Schene, 2015). However, due to the erratic nature, elusive and prolonged clinical course of depression, experiences on how to cope with depression may be unique per individual. Also, different demographic and clinical characteristics such as gender identification, age, history of depression, symptom severity, the presence and experience of social support may determine developmental processes of experiential knowledge. Hence, individual experiential knowledge may differ from one another. Synthesizing individual experiences may clarify similarities in coping with depression, which are probably useful for peers, and could be included clinical research, recovery-oriented services, and practice. To acknowledge the unique experience per individual, though simultaneously identify universal themes in the pathway to recovery, exploring the patient perspective may serve as a fruitful starting point (Herrman et al., 2022).

In general, the concept of experiential knowledge refers to "patient's unique knowledge and own lived experiences in helping and debilitating factors in the recovery process and coping with the disorder" (Boevink, 2017; Borkman, 1990; Burda, van den Akker, van der Horst, Lemmens, & Knottnerus, 2016). Multiple wide-ranging themes emerge when reviewing the literature on this phenomenon, that may interact and are potentially overlapping (Cerezo, Juvé-Udina, & Delgado-Hito, 2016): autonomy (Damsgaard, Overgaard, & Birkelund, 2021), self-management (Grieken, Kirkenier, Koeter, Nabitz, & Schene, 2015), self-efficacy (Burke, Pyle, Machin, Varese, & Morrison, 2019), and empowerment (Leamy et al., 2011). In particular empowerment is considered a key aspect in recovery-oriented practice and experiential knowledge since, once again, the concept is echoed in the philosophy of the Consumer Movement. The criticism on the paternalistic nature of the mental health system, instead of encouraging the strong aspects and capabilities of the individual patient is central to empowerment, with elements of hope (Burke, Pyle, Machin, & Morrison, 2018), overcoming stigma (Burke et al., 2018; Burke et al., 2019; Chan, Mak, & Lam, 2018), generally referring to "a greater ability to exercise control, manage the condition and make informed decisions" (Cerezo et al., 2016). Empowerment is used in many settings, entailing many visions, community levels, processes and outcomes (e.g., individual and collective processes at organizational and political levels; Halvorsen et al., 2020; Miguel, Ornelas, & Maroco, 2015; Zimmerman, 1995).

Peer Support

Principally, peer support is based on giving and receiving help with the use of own lived experiences (Mead, Hilton, & Curtis, 2001; Solomon, 2004), and central themes of "respect, shared responsibility, and mutual agreement of what is helpful" (Mead, 2003 ; Repper & Carter, 2011). In broader context, including theories of social science and anthropology, processes of social bonding (Ghosh, 2014), having examples from role models (e.g., *Self-efficacy model;* Bandura, 1977), and engaging in a community where people are equal and share a common experience (e.g., the antrophological philosophy *Communitas* of Turner; Goodman & Goodman, 1947) collectively provide the bedrock of peer support. Hence, reciprocity by sharing similarities in values, beliefs, and attitudes are considered central aspects. However, there are multiple definitions of peer support, owing to the variety of intervention types, deployment across different (patient) groups and service delivery settings (Chinman et al., 2014; Shalaby & Agyapong, 2020).

Both in the Netherlands and internationally, peer support initiatives primarily target a broad group of patients with SMI (Biagianti, Quraishi, & Schlosser, 2018; Cabassa, Camacho, Velez-Grau, & Stefancic, 2017; Chinman et al., 2014; Fortuna et al., 2020; Fuhr et al., 2014; Lloyd-Evans et al., 2014) with a smaller proportion including individuals with depression (Bryan & Arkowitz, 2015; Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011), elevated mental health symptoms (Burke et al., 2019; Pitt et al., 2013), or more specific subgroups such as perinatal depression (Huang et al., 2020), or caregivers of psychiatric patients (Bademli & Cetinkaya Duman, 2011). The majority of these services is fully delivered by peers (i.e., not [co-]led by a [para-]professional), in a one-to-one, face-to-face setting, and with flexible frequency (Boevink, Kroon, van Vugt, Delespaul, & van Os, 2016a; Castelein et al., 2008; Cook et al., 2012a; O'Connell et al., 2018; Pfeiffer et al., 2019; Ranzenhofer et al., 2020; van Gestel-Timmermans, Brouwers, van Assen, & van Nieuwenhuizen, 2012; Wedema, 2022).

Digitalisation of Peer Support. To inform the Dutch government and its' funding parties, national patient associations (e.g., the Dutch Foundation for mental problems [MIND]; MIND, 2022; the patient assocation for Anxiety, Compulsion, and Phobia [ADF-stichting]; ADF, 2022; and Enik Recovery College; ENIK, 2022) together with federations of mental health care professionals set research agenda's, prioritizing topics that should gain more attention to improve support for patients in their recovery pathway (e.g., The Dutch Association of Mental Health and Addiction Care [de Nederlandse GGZ, 2022]; Federation of Psychologists, Psychotherapists, and Pedagogues [P3NL, 2022]; and The Association for Psychiatry [NVvP, 2022]). One of the current topics addresses the uptake of eHealth services (P3NL, 2022), which is supported by meta-analytic evidence, suggesting that (guided) internet-delivered therapies are equally effective to face-to-face treatment (Andrews et al., 2018; Karyotaki et al., 2021). Also, online mental health services expanded during the COVID-19 pandemic (Suresh, Alam, & Karkossa, 2021) due to measures of social distancing. eHealth is cost-effective to implement and do not rely on the scarce resource of mental health care provides (Butryn, Bryant, Marchionni, & Sholevar, 2017; Wainberg et al., 2017). Still, the majority of peer support services is delivered in offline (face-to-face) settings. In addition to the above-mentioned organizational benefits (i.e., equal efficacy and increased availability of support), online formats may also have potential benefits for the individual patient. In particular for depression, the online 24/7 accessibility may lower the threshold to engage when the individual is having sleep problems (with e.g., peek rumination during the night time; Koster, De Lissnyder, Derakshan, & De Raedt, 2011), and is struggling with symptoms such as passive behavior or a loss of interest in activities (Patten, 1999). Also, the possibility for anonymous engagement may help to circumvent its associated stigma (Houston, Cooper, & Ford, 2002).

Depression Connect, the Online Peer Support Community. Together with individuals with depression, their significant others and health professionals (psychiatrists, therapists, and researchers), and following the methodology of Human Centered Design Thinking (Oppl & Stary, 2019), we explored how to deploy experiential knowledge for individuals with depression. In an attempt to answer to the need for digital and widely accessible peer support tools, we co-created a new online peer support community for depression: "Depression Connect" (DC; Depressie Connect, 2022). DC is a digital platform that offers individuals with depression to (anonymously) read or exchange knowledge about and experiences with coping with depression. Though outside the scope of this thesis, we added a separate digital platform to DC for relatives of people with depression. Hence, we facilitated the exchange of experiences among relatives that were living with, or close to, someone with depression.

Main Principles Depression Connect. DC is based on the following principles: (a) developed in a co-creation; (b) hosted by the national patient association; (c) focus on future perspectives in coping with depression; and (d) freely accessible for anyone dealing with depression.

a. *Developed in a Co-Creation*
We organized focus groups with many stakeholders (i.e., individuals with depression, their relatives, researchers, therapists, psychiatrists) to agree upon an appropriate method to inform individuals with depression on coping with depression according to their peers. As a leading party in this co-creation, individuals with depression expressed a clear need for *peer* support, and *exchanging experiential* instead of *transferring professional* knowledge.

b. *Hosted by The National Patient Association, the Dutch Depression Association*
Playing a central role in organizing peer support facilities for individuals with depression in the Netherlands, the Dutch Depression Association (Depressie Vereniging, 2022) hosts the platform with all coordinators and moderators being experiential experts. No professionals are involved in DC, though a psychiatrist and psychology researchers of our team could be consulted when feedback is needed.

c. *Focus on Future Perspectives in Coping With Depression*
To ensure a constructive atmosphere, we introduce engagement rules for new users explaining to them that our peer support platform is focused on how to cope with depression, and thus learning how to manage with difficulties that are associated with living with depression. Yet, we encouraged users to be open about struggling with depression (including suicidal ideation though not discussing concrete suicidal tendencies or plans) provided that engagement rules were adhered. Moderators screen all posts twice a day to monitor safety and foster topical relevance.

d. *Accessible for Anyone*
Depression Connect is freely and 24/7 accessible for anyone dealing with depression. Any interested user can sign up for DC-membership. To access the content of the community, members always need to login.

Aim and Research Questions

Although peer support is rapidly growing internationally (Stratford et al., 2017), research remains relatively scarce and evidence is limited (Burke et al., 2019; Lloyd-Evans et al., 2014; Pfeiffer et al., 2011). Effectiveness research is complex due to various reasons: The unclear and varying definitions of peer support as described earlier, make it difficult to properly disentangle aims and outcomes. Also, the settings of the delivered interventions (e.g., online versus offline), formats (e.g., group versus individual), and populations (e.g., individuals with SMI versus subthreshold symptoms) are very heterogeneous. Last, also mentioned before, the target outcome varies between clinical, personal, and functional recovery. As such, currently available meta-analyses on Peer Support Interventions (PSIs) for mental health issues focused on specific intervention types (Lyons, Cooper, & Lloyd-Evans, 2021; White et al., 2020), target outcomes (Chien, Clifton, Zhao, & Lui, 2019; Huang et al., 2020), or populations (Bryan & Arkowitz, 2015; Huang et al., 2020); this selectiveness possibly leading to limited power of the meta-analyses. This limited evidence and limited scope of studies for PSIs seems to hinder structural funding to implement peer support services in clinical practice. Therefore, it is necessary to systemically and comprehensively review the empirical literature on PSIs that seek to promote recovery on clinical, personal and functional life domains, across different settings, and intervention formats.

Additionally, there is a need to know which processes in (online) peer support might foster change (Watson, 2017). In real-world settings, users with widely varying clinical and demographic characteristics, can engage in PSIs with different participation styles or intensity levels, and might benefit from the informal character of peer support including aspects that are not quantifiable. Qualitatively explored user experiences of engaging in an online depression PSI could gain insight in the processes behind peer support, that may subsequently be addressed in peer support research and interventions to increase its potential efficacy.

Taken together, building on the recovery-oriented approach in mental health care, the use of experiential knowledge and engaging in peer support services might encourage individuals with mental illness to progress their pathway to recovery. By combining in-depth qualitative interview data, quantitative data of a user survey, and meta-analytic methods, this thesis aims to thoroughly examine the development of experiential knowledge and the benefits of engaging in peer support in the pathway to recovery in mental illness, and more specifically depression.

Methodology

A key challenge for scientific research on the recovery pathway for depression (including the personal nature of the journey, experiential knowledge, and the informal character of peer support) is to incorporate appropriate research methods to capture these dynamic processes. We explored the patient's perspective on how to learn to cope with depression (interview study on the development of experiential knowledge), and examined both qualitatively (interview study) and quantitatively (longitudinal user survey) the usefulness of engaging in online peer support. Last, to broaden our perspective and seek for empirical evidence for peer support for wide-ranging mental health problems, we used meta-analytic methods and pooled data of randomized controlled trials (RCTs) comparing peer support to a control condition.

Table 1 provides an overview of the research questions including the methods used to answer this question, as discussed in each chapter.

Table 1. *Research Questions per Chapter*

Research question		Methods	Chapter
1	What do individuals with depression learn when coping with depression? What is needed to deploy self-management strategies for depression?	Explorative qualitative interview study	2
2	What are the perceived benefits of engaging in the online peer support community Depression Connect? Are user experiences related to participation styles?	Thematic qualitative interview study	3
3	What is the intensity and nature of user engagement in the online peer support community Depression Connect, and is this related to changes in recovery-related outcomes?	Quantitative user survey	4
4	Are peer support interventions for individuals with mental illness effective for clinical, personal, and functional recovery?	Systematic review and meta-analysis	5

Outline of The Thesis

To gain insight in the main themes of experiential knowledge for depression, and its potential relation with self-management, we interviewed individuals with (chronic or recurrent) depression in our study in **chapter 2**. Building on these findings, with experiential knowledge considered the core of peer support, we developed the online peer support community “Depression Connect” (DC), the object of our two follow-up studies. In **chapter 3** we evaluated user experiences of engaging in the online peer support community, with a possible link to participation styles. In this study, we interviewed DC-users about their perceived benefits, and analysed participation styles in the qualitative data. In addition, **chapter 4** quantitatively describes the intensity level and nature of user engagement in our online peer support community, exploring it association with changes for empowerment, self-management, depressive symptoms, and functioning and disability. In **chapter 5**, we adopted a broad perspective, and examined the effectiveness of peer support interventions across a wide range of mental illness, intervention types and outcomes in a systematic review and meta-analysis. This thesis ends with a discussion of the findings, limitations, recommendation for future research and implications for clinical practice in **chapter 6**.

CHAPTER 2

An Exploration of The Conditions for Deploying Self-Management Strategies: a Qualitative Study of Experiential Knowledge in Depression

Smit, D., Peelen, J., Vrijsen, J. N., & Spijker, J. (2020). An exploration of the conditions for deploying self-management strategies: a qualitative study of experiential knowledge in depression. *BMC psychiatry, 20*(1), 1-11. doi: 10.1186/s12888-020-02559-3

Abstract

Background: Living with recurrent, and/or chronic depression requires long-term management in addition to active coping on a day-to-day basis. Previous research on long-term management, and coping with depression mainly focused on identifying self-management strategies. However, research on the conditions for deploying self-management strategies in depression is lacking. By means of exploring the development of experiential knowledge in depression, and its relation with coping with depression, this study aims to gain insight into the conditions for deploying self-management strategies.

Methods: In the current qualitative study, individual pathways to recovery, living with depression, and recurrence risk were assessed, including but not limited to long-term management. "Experiential knowledge", which can be defined as patients' unique knowledge and own lived experiences in facilitating and debilitating factors in the recovery process and coping with the disorder, was used as a sensitizing concept. Thirteen semi-structured interviews were conducted with individuals who experienced at least two depressive episodes and were currently in (partial) remission, plus two deviant cases were interviewed to check for saturation. Until saturation was achieved, participants were purposively selected to include diverse perspectives on coping with depression. Data were analyzed using a narrative research method.

Results: The results show that deploying self-management strategies are an integral part of "experiential knowledge". The evolvement of experiential knowledge can be seen as a cyclical process of the main themes that were identified as relevant when coping with depression: introspection, empowerment, self-management strategies, and external moderators of the environment. The identification of supporting and impeding factors in coping with depression from a patient perspective might increase a sustainable use of self-management strategies.

Conclusion: These results highlight the need for an individualized holistic model of coping with depression, both in research, and in practice. By means of integrating experiential knowledge in this holistic approach, the conditions for deployment of self-management strategies in depressive patients can be specified.

Introduction

Depression is a growing global health problem, associated with significant social and physical disability, mortality, and economic burden (Moussavi et al., 2007). It is considered to be a chronic illness: recurrence rates are high around 60% after 5 years, rising to 85% after 15 years (Hardeveld, Spijker, De Graaf, Nolen, & Beekman, 2010; Richards, 2011). Almost 20% of all patients develop chronic depression (≥ 2 years of symptoms) (Gilmer et al., 2005; Penninx et al., 2011). Moreover, approximately 50% of depressed patients respond insufficiently to treatment (Greden, 2001; Nemeroff, 2007). The chronic nature as well as suboptimal treatment response is indicative of the fact that depression requires long-term management (De Ridder, Geenen, Kuijer, & van Middendorp, 2008; Keitner, Ryan, & Solomon, 2006; Richards, 2011).

In recent years the view on mental disorders has shifted from a primary focus on symptom reduction to including the acknowledgement of the importance of coping with problems related to the mental disorder (Jacob, 2015; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Van der Stel, 2015). Previous studies on coping with depression concentrated on the concept of self-management (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Self-management is defined as “the training, skill acquisition, and interventions through which patients who suffer from a disease or chronic condition may take care of themselves and manage their illnesses” (Yeung, Feldman, & Fava, 2009, p. 1). Specifically, research has been aimed at identifying self-management strategies. Engaging in sports activities and having a good day and night rhythm are examples of strategies that are perceived as helpful when coping with depression (Morgan & Jorm, 2009; van Grieken, Kirkenier, Koeter, & Schene, 2014; Villaggi et al., 2015). Collectively, the results indicate that deploying self-management strategies can provide a positive contribution to recovery and coping with depression, such as lower depressive symptoms, an improvement of self-efficacy, and empowerment (Houle, Gascon-Depatie, Bélanger-Dumontier, & Cardinal, 2013; Johnson et al., 2018; Ludman et al., 2015). However, the way in which self-management strategies in depression treatment are dealt with has been criticized as being overly simplistic, because symptoms of depression (such as passive behaviour) can interfere with self-management (DiMatteo, Lepper, & Croghan, 2000; Greenhalgh, 2009). Moreover reduced self-confidence and energy, and/or an increased state of confusion caused by the many choices in strategies can impede the use of self-management (DiMatteo et al., 2000; Morgan & Jorm, 2009). In fact, the inability to engage in self-management can lead to feelings of helplessness and hopelessness (De Ridder et al., 2008; Lustman, Freedland, Griffith, & Clouse, 2000), which contributes to the depression (Morgan & Jorm, 2009). Therefore, more knowledge about the implementation of coping with recurrent and/or chronic depression, including the conditions for deploying self-management strategies, is of major importance.

The use of *experiential knowledge* is an important feature in coping with a somatic or mental disorder. The concept of experiential knowledge refers to patients' unique knowledge and own lived experiences in helping and debilitating factors in the recovery process and coping with the disorder (Blume, 2017; Boevink, 2017; Burda, van den Akker, van der Horst, Lemmens, & Knottnerus, 2016; Slomic, Christiansen, Soberg, & Sveen, 2016). There is a relatively small body of literature concerning experiential knowledge. To date, studies focused on the effect of deploying experiential knowledge by adding peer support to treatment as usual for individuals with chronic illnesses, such as somatic disorders and physical disability (Burda et al., 2016; Burda et al., 2012; Fox, 2005), as well as psychotic disorders and trauma exposure (Boevink, 2012; Lloyd-Evans et al., 2014; Van der Schaaf & Oderwald, 1999). Although some positive effects on hope, recovery, and empowerment were found, these results should be interpreted with caution because of the limited number of studies, the complexity, and variety of interventions (Lloyd-Evans et al., 2014). Moreover, there is a lack of clarity about the substantive themes that are associated with the concept of experiential knowledge. Hence, a deeper understanding of experiential knowledge, in which helping as well as debilitating factors in coping with the disorder are defined, could shed light on the conditions for deploying self-management strategies. Research on experiential knowledge in depression is currently lacking. To give an in-depth description of coping with recurrent and/or chronic depression, the concept of experiential knowledge should be examined.

This qualitative study aims to explore the relation between the development of experiential knowledge and coping effectively with depression, as well as the conditions for deployment of self-management strategies. Semi-structured interviews were conducted in a heterogenic group of individuals who have experience with depression (> 2 past episodes).

Methods

Design and participants

A qualitative semi-structured interview study design was used. Experiential knowledge was approached as a sensitizing concept. As explained by Boeije (2009, p. 23), sensitizing concepts start out with a general description, because they are not yet specified and clarified in the research field. In this research, the general description of experiential knowledge was used as a guiding framework for exploring an in-depth characterization of the construct from a patients' perspective. Fifteen face-to-face interviews, with open-ended questions about personal experiences in coping with the illness, were conducted with individuals who experienced at least two depressive episodes over the course of three years minimum, and were currently in (partial) remission (see Appendix A for the interview guide). Members of the Dutch Depression

Association were approached for participation. Furthermore, recruitment took place via national and regional news websites about mental health care. Data collection continued until saturation was reached, that is when no new topics emerged during the interviews. To check for saturation, deviant cases were included; one individual with a current depression, and one individual who experienced a single depressive episode.

Participants had to meet the following criteria: (a) two or more past depressive episodes (except for one deviant case), (b) the first depressive episode had occurred at least three years prior to participation. These criteria were used to ensure participants' ability to reflect on their depressive experiences during the interviews. The following exclusion criteria were used: age younger than 18 years, a current depressive episode (except for one deviant case), bipolar-, or (a history of) psychotic disorder, current drug abuse, and current severe risk of suicidality. Eligibility was assessed by telephonic administration of the brief structured diagnostic interview Mini International Psychiatric Interview for DSM-IV-TR [MINI] (Lecrubier et al., 1997; Overbeek, Schruers, & Griez, 1999).

Throughout the entire duration of this study, thirty-four people were interested in participating in the interview study. Participants with diverse clinical and demographic characteristics (e.g. number of depressive episodes, age, ethnicity, educational level) were included to increase conceptual variation. These characteristics were examined by telephonic screening before conducting the MINI interview (see Appendix B). As a result, sixteen people were not included. Moreover, according to the exclusion criteria three participants were excluded due to a current depression, drug abuse or the experience of several psychoses during depressive episodes. This resulted in fifteen study participants (eight men, seven women; including two deviant cases). Table 1 shows the participants' demographic and clinical characteristics.

The local ethics committee [Commissie Mensgebonden Onderzoek Arnhem-Nijmegen] assessed the research protocol for this study. According to the regulations of the Medical Research (Human Subjects) Act, they stated that further approval was not deemed necessary given the minor burden of participation in this study.

Table 1. *Demographic and Clinical Characteristics of Study Participants (N = 15)*

Characteristic	**Full sample**	
	n	**%**
Gender		
Male	7	47
Female	8	53
Membership Dutch Depression Association		
Yes	7	47
No	8	53
Ethnicity		
Dutch	11	73.3
Surinamese/Antillean	1	6.7
Serbian/Croatian	1	6.7
Surinamese/Hindustani	1	6.7
Dutch Antillean	1	6.7
Educational level		
Secondary education	3	20
Secondary Vocational Education and Training	1	6.7
Higher education (research-oriented and profession-oriented)	11	73.3
Treatment history type [a]		
A form of therapy in mental health care (i.e. CBT, psychodynamic psychotherapy)	15	100
Former use of medication	5	33
Current use of medication	7	47
Never used medication	3	20
Number of depressive episodes [b]		
One episode (negative case)	1	6.7
Two episodes	1	6.7
3-5 episodes	7	47
> 5 episodes	4	26.6
Chronic course only (≥ 2 years of symptoms)	2	13.3
Chronic course in addition to depressive episodes	4	26.6
Age at onset (*years*) [c]		
12-18	5	33.3
19-25	3	20
26-32	3	20
33-45	3	20
≥ 46	0	0
Unknown	1	6.7

Characteristic	**Full sample**	
	n	**%**
Years since onset (*years*) [d]		
0-10	2	13.3
11-20	4	26.6
21-30	6	40
31-40	2	13.3
41-50	1	6.7

Note. Participants were on average 43.5 years old (*SD* = 15, range 23-67). Abbreviation: CBT = Cognitive Behavioral Therapy.

[a] Including overlap between the categories (e.g., participants using medication and receiving psychotherapy)

[b] Including overlap between the categories (i.e., individuals reporting a chronic course and single depressive episode(s))

[c] Age at depression onset ranged from 12 to 45 years old.

[d] The duration of experiencing depressive episodes or chronic depression ranged from 10 to 45 years.

Interviews

Confidentiality was guaranteed to the participants. Information about the study was given in oral and written form. Informed consent was signed before starting the interview. In the semi-structured interview, participants' underlying ideas of behavior, choices and thoughts in coping with depression were explored. The main question in the interview was "What did you learn while living with depression?". To ensure that the main topics of the research question were discussed by all participants, an interview guide was produced based on literature, preliminary consultation and orienting interviews with social scientist researchers, a psychiatrist, and patients. The topics were clustered in five discussion topics, which are presented in Table 2 (see Appendix A for the full interview guide). The interviews were conducted by one researcher (author DS). The interview guide was modified after finishing the third, fifth, ninth and eleventh interview, so that new emerging topics could be further explored.

Interviews were conducted between May 2018 and August 2018. The average duration of an interview was 73.6 minutes (Range = 45-89, *SD* = 13.9). When participants were perceived to be in psychological stress or reported discomfort, ending or pausing the interview was suggested. Although no interview was ended prematurely because of participants' distress, one interview was temporarily paused because of participants' emotional experiences. All interviews were audio recorded and transcribed verbatim into written text as accurately as possible, including pauses, and non-verbal sounds. Identifying information such as the names of individuals were removed during the transcription process.

Table 2. *Topics Interview Guide in Keywords*

Main Discussion Topics	Subtopics
Course of the disorder	Experiences depressive episodes, triggers, development of the depression
Coping with depression	Dealing with the illness, practical skills, personal characteristics, supportive network
Self	Self-reflection, influence of experiencing depression on identity
Experiential expertise	Opinion on the role of experiential knowledge and -expertise in mental health care
Mental health care	Experiences with treatment for depression

Note. Complete interview guide available, see Appendix A.

Analyses

Data were qualitatively analysed in accordance with a narrative research method, focusing on the perspective of the information (who said it), what and how it is narrated (Bal, 1997, p. 3). Atlas.ti software (version 8) was used for the coding process. After the first two interviews two researchers (authors DS and JP) examined the transcripts. This open coding process began with line-by-line microanalysis aimed at identifying categories within the data. The two researchers (DS, JP) used independent coding to ensure inter-coder reliability. The researcher (DS) continued the analysis progressing to axial coding, by condensing codes, exploring categories, their properties, and the relationships between them (Boeije, 2009, pp. 108-114). To ensure the validity of the ongoing data analysis, the process of coding was discussed with two independent researchers. Interim findings informed the process of purposive sampling, and adjustments of the interview guide.

In addition, two member checks, after the analysis of eight and subsequently eleven interviews, were held to validate the analysis. These meetings were attended by respectively three and four participants. Also, to discuss study results from a broad perspective, a focus group was conducted after finalisation of data collection. This meeting was held with six independent experiential experts (non-participants, recruited via diverse websites for mental health care and the Dutch Depression Association) and four health care professionals of depression (psychologists and psychiatrists, recruited via Radboud University Medical Centre and the Pro Persona mental health care institution). By initiating a group discussion to reflect on the results of the qualitative study, the interim findings were validated, no new main themes were found. However, a lack of attention for physical wellbeing in mental health care, and limited focus on involving relatives in treatment were brought up as underexposed factors.

Concerning the influence of the researcher to the interview process and to the participants, a reflexive logbook was kept. Limited clinical and personal experiences with depressive patients and the absence of any formal role (regarding treatment) between participant and researcher, aided to remain open and contributed to an objective stance.

Results

The development of experiential knowledge

Results indicate that experiential knowledge evolves from three intrapersonal levels: (a) in a process of *introspection*, (b) in the development of *empowerment*, and (c) in learning and deploying *self-management strategies*. Finally, external moderators of the evolvement of experiential knowledge seem to appear at an interpersonal level, which are described under (d) *the environment*. Constant interaction between these three intrapersonal levels as well as interaction between an interpersonal process and intrapersonal factors is observed in the data.

The main themes as well as subthemes derived from the narratives are presented in Table 3. Excerpts from various respondents are used throughout the presentation of results. The quotes are illustrative of the complex, ongoing development and interaction of different aspects in coping with depression. Together they should provide the reader with a comprehensive picture of the developmental pathway of experiential knowledge. Participants are numbered randomly (P1, P2, etc.).

Table 3. The Development of Experiential Knowledge in Long-term Depression

	Main themes of experiential knowledge	**Subthemes**
1.	Introspection	Self-reflection
		Self-compassion
		(Self-)acceptance
		Meaning-making
2.	Empowerment	Autonomy
		Self-confidence Future perspective
3.	Self-management strategies	Daily schedule/structure
		Activities
		Self-help
		Contact with others
4.	The environment	Societal context
		Mental health care
		Social support

Introspection. The evolvement of experiential knowledge seems to start with the realization of "disconnection". Data revealed that nearly all participants lost connection with themselves, with others, and with society, while suffering from depression. Feelings of loneliness were reported. Three depressive patients described this disconnection as "wearing a mask", explained as misrepresenting oneself by hiding or neglecting negative feelings:

> *Actually, I was wearing a mask, and I kept pushing forward. That is what exhausted me at the end of the day, because I had to pretend I was okay, while sometimes I did not manage to carry on.* (P6, woman, 33 years old, Dutch Antillean)

When participants managed to get rid of their "masks" they mentioned a responsiveness to learn about their own character, background, desires, strengths, and vulnerabilities. This process is referred to as introspection. Breaking down the concept of introspection, four processes can be discerned: self-reflection, self-compassion, (self-)acceptance, and meaning-giving.

Self-reflection entails the personal examination of the own conscious thoughts and feelings, which increase the understanding of relapse triggers:

> *By discovering my main three negative thoughts, I was able to recognize that the other thousands negative thoughts were linked to them. A very organised list of thoughts was formed, which cleared my mind because I had the common sense to understand what my triggers were.* (P8, Man, 27 years old, Dutch Antillean)

More than half of the participants mentioned *self-compassion* as important in coping with depression. Being kind, attentive and patient with oneself, and to ignore the critical inner voice or expectations of others, are mentioned as facilitators in dealing with the disorder:

> *If you can accept that normal activities in life are difficult to succeed when you are depressed, you can let go of the pressure and expectations towards yourself. So, you won't disappoint yourself all the time.* (P11, Woman, 25 years old, Dutch)

(Self-)acceptance comprises the acceptance of depression as an illness and acceptance of the self, with one's positive and negative characteristics, as is intertwined with self-compassion:

> *For me, acceptance is feasible by means of meditation. Because of the mild attitude and gentleness: "anything goes". Before, I was fighting against all those negative thoughts, the opposite of accepting emotions. I attended a mindfulness and compassion-training. The gentleness is healing and lowers the impact of negative thoughts and emotions.* (P2, Man, 46 years old, Dutch)

To develop experiential knowledge by means of acceptance, half of the participants suggested that it is crucial to consider depression as a disease, and explicitly not to consider depression to be an integral part of one's identity:

> *I consider it as an illness which can be dealt with. When you consider depression as a part of your identity, it will be very difficult to manage because actually, you are fighting against yourself. That doesn't make sense.* (P1, Man, 23 years old, Dutch)

Finally, *meaning-making* entails the active engagement in the act of making sense of living with depression. The meaning that participants attributed to depression was unanimously described as increased self-knowledge, a desire to help fellow sufferers, and a grateful attitude in life:

> *Many times, I have said coping with depression enriched me. I do not want to experience it all over again. However, I discovered things that I did not notice before, or was not able to appreciate. In fact, I live a more conscious and a - somewhat overstated - grateful life.* (P3, Woman, 38 years old, Serbian/Croatian)

Whereas acceptance of depression appears to be a necessity for meaning-making, it is considered very difficult by four participants, mainly because of the caused misery in their life:

> *Perhaps, I find acceptance overstated, because I hate it when I feel it is kicking in. When you lived with depression for nine years, you know how it feels, it can torment you to the bones. I can recognize the depression, but really accept it, no.* (P8, Man, 27 years old, Dutch Antillean)

Taken together, a deepened self-understanding by means of introspection appears to be of major importance to develop experiential knowledge. In fact, the more an individual knows about the self, adopts a mild attitude, and develops acceptance towards the depression, the more personal experiential knowledge arises on how to effectively deal with the illness.

Empowerment. The data revealed three competencies associated with empowerment: autonomy, self-confidence, and having a future perspective. In the interviews, all participants described regaining individual responsibility and grip on life, i.e. autonomy as a tipping point in the capability to manage the depression in a healthy way:

> *I used to give responsibility to someone else (…). I blamed my family, my friends, my illness. I always thought things happened to me, that I was not in control. Then, I realised you can create your own life, there is always a choice. You do*

> *not have to wait for support or... you just have to do it yourself. At that point, I knew I was strong enough to take care of myself and make my own decisions.* (P3, Woman, 38 years old, Serbian/Croatian)

A third of the participants explained that being autonomous requires courage; (new and/or individual) choices are often about taking risks. This explanation shows that autonomy is interrelated with *self-confidence*. Both competencies are considered to be important as it helps to pursue personal values and wishes, instead of adjusting to the barriers of depression or wishes of others. The data show that it takes a considerable amount of positive events in daily life to develop autonomy and self-confidence, i.e. a feeling of trust in one's abilities, qualities, and judgement:

> *Try something new, something very small and insignificant. For example, change your sandwich filling. If you do enough of these new, little things, a feeling of fulfillment and a bigger shift of perspective may be the result. Hence, you could break the vicious circle of the depression (...). Moreover, you feel more autonomous, making your own choices gives you a feeling of control, you will feel more alive.* (P7, Man, 67 years old, Dutch)

Furthermore, thinking and acting based on a *future perspective* facilitates empowerment. It contributes to personal fulfilment. Having a purpose in daily life, such as taking care of children or relatives, having an interesting job or looking after pets are important in developing this competency:

> *For me, work is the best way for recovery. It gives meaning in life, and a sense of fulfilment. Yes, work keeps me going.* (P12, Woman, 44 years old, Dutch)

Empowerment involves the ability of an individual to make one's own choices, which are in line with personal needs, a belief in oneself, and a future perspective. Feeling empowered seems to be of practical significance in the evolvement of experiential knowledge, because results suggest that this competency facilitates coping adequately with depression.

Self-management strategies. Experiential knowledge, specified as empowerment and introspection, appears to unfold by means of self-management strategies. Respondents referred to self-management strategies as practical coping skills when managing the challenges of depression on a day-to-day basis, including the risk of a relapse. The narratives indicate that living with recurrent and/or chronic depression requires a long-term deployment of self-management strategies in life. Whereas dealing with the symptoms of a current depression involves a more acute implementation of self-management strategies that are meant to control the condition:

> *In the “red phase”, when a depressive episode starts, I take as much rest as possible and some extra medicine. I need sufficient rest, enough sleep, and no stress. A daily structure helps because it is important to respect my own boundaries, physically and mentally (…). Next, in the “orange phase”, it is important to be aware of my emotions and to meet someone who listens to me. Talking helps to organise my thoughts. At the last stage, “green”, it is important to think about the future, to do pleasurable activities and to engage in social contact with others. For me these things are impossible in the first stages.* (P9, Woman, 60 years old, Dutch)

Strategies might be divided into acute self-management strategies: daily schedule or structure and engaging in activities, in addition to long-term self-management strategies: self-help and contact with others. First, creating a *daily schedule or structure* was indicated as an effective self-management strategy at the initial stage of a depressive episode. It helped respondents to take rest and acknowledge depressive symptoms. In addition to planning their daily lives, participants suggested taking medication, sleep, and staying in familiar surroundings. Secondly, engaging in *activities* was described as doing pleasant and low-threshold activities in a familiar environment. Activities that involved social interaction and exercising were especially helpful, as these activities contributed to self-confidence. The long-term self-management strategy *self-help* helped participants to engage in self-reflection and taking rest. Interviewees mentioned self-help methods such as writing about personal experiences, meditation, mindfulness, reading inspiring self-help books or watching YouTube movies about personal development. Finally, participants indicated the strategy to establish or maintain *contact with others,* contributing to a sense of belonging. Respondents emphasised the importance of openness and an equal nature of social interaction. As follows from the data, the deployment of self-management strategies interacts with the evolvement of empowerment and introspection, i.e. experiential knowledge. It seems that both categories of self-management strategies need to be adjusted to the personal context of depression in order to be meaningful. As follows from the data, the deployment of self-management strategies interacts with the evolvement of empowerment and introspection, i.e. experiential knowledge:

> *If you want to offer resistance against depression, you need three stages in my experience. To begin with, you have to be kind to yourself. Try to find activities that give a little bit of pleasure. The second stage consists of a mindful attitude towards your environment, a gentle lens. So, if you are outside, maintain a moment-by-moment awareness of your surrounding environment, for example by looking at the clouds. Then, stage three is the opposite of this gentle attitude. When you are recovering, you have to demand yourself to do things because it will give a good feeling to succeed.* (P7, Man, 67 years old, Dutch)

In summary, carrying out self-management strategies seems to be a manifestation of experiential knowledge, and thus introspection and empowerment. In this process, more knowledge about dealing effectively with the illness has arisen.

Important external moderators: The environment. In this research, the focus on the evolvement of experiential knowledge lies on intrapersonal levels. However, the data also reveal that the evolvement of experiential knowledge cannot be fully understood without acknowledging the complex set of influential factors in the environment of the individual which unfold at an interpersonal level. Factors in the environment are clustered in the societal context, mental health care, and social support systems. They individually and interactively influence the processes at an intrapersonal level, i.e. introspection, empowerment, and self-management strategies.

When discussing the *societal context,* the experience of discrimination and stigma was mentioned as an impeding factor of coping with depression by *t*hree-quarters of the respondents. While openness about depressive feelings is perceived to be helpful in coping with the disorder:

> *We never spoke about it at home. My parents knew there was something wrong, but they could not see what it was. For me, that was very difficult because of the loneliness. In retrospect, discussing it openly was good. In my experience, depression is still a taboo subject. As, if I said "I have asthma", there is no taboo at all.* (P1, Man, 23 years old, Dutch)

In *mental health care*, particularly developing self-reflection is mentioned as contributing to the development of experiential knowledge:

> *Self-reflection is not 'just there'. It took many years to develop. With the help of individual treatment in mental health care, my self-knowledge increased by leaps and bounds.* (P15, Man, 62 years old, Dutch)

Thirdly, the importance of *social support* from peers, family and friends in the evolvement of experiential knowledge is reflected in all narratives:

> *There were friends who saw me as an independent person, ignoring the impact of the depression on my appearance. My friends made positive change. They kept supporting me, they kept believing in me, treated me positively. The connection I felt with this group of friends lead to a feeling of acceptance, which had a positive impact on my day-to-day functioning.* (P10, Woman, 55 years old, Dutch)

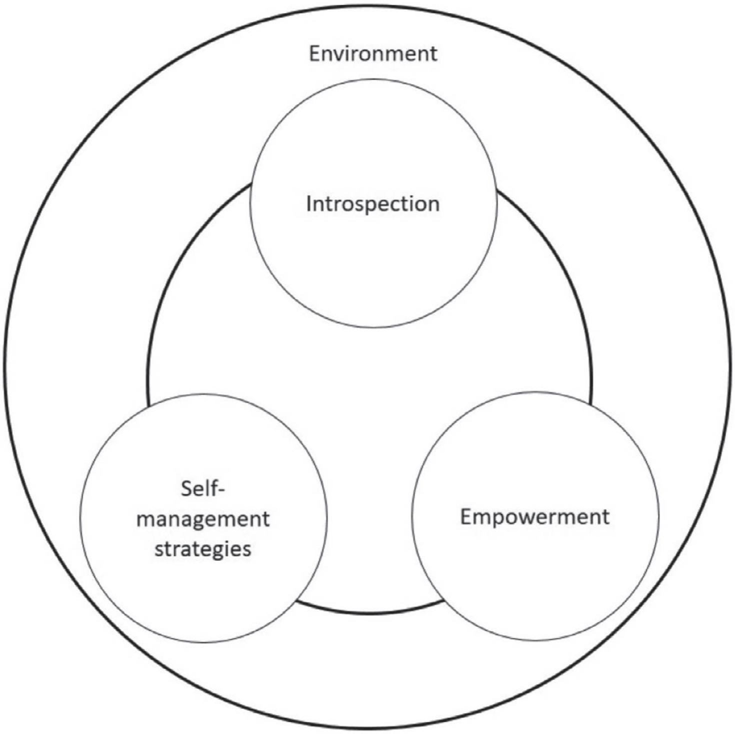
The data reveals that the environment can stimulate or impede coping with depression as well as the evolvement of experiential knowledge. The ability to deal effectively with the disorder can be influenced by various factors in the environment, which are unique per individual.

Discussion

Main Findings

The current study examined the evolvement of experiential knowledge in depression. The relation between experiential knowledge and coping effectively with depression, as well as the conditions for deployment of self-management strategies when coping with depression were explored. The results show that from the patients' perspective, experiential knowledge evolves from three intrapersonal levels: introspection, empowerment and self-management strategies, and one interpersonal level: the environment. Specifically, the data show a continuous interaction among the intrapersonal levels and interpersonal level of experiential knowledge, suggesting that the evolvement is a cyclical process, as shown in the figure below.

Figure 1. *The Development of Experiential Knowledge in Recurrent and/or Chronic Depression*



Experiential knowledge, in terms of introspection, empowerment, self-management strategies, and facilitating and impeding factors in the environment, seems to contribute to how well patients can cope with depression. As follows from the data, it could be hypothesised that a positive interaction between these processes lead to the sustainable deployment of self-management strategies. Firstly, through a deepened self-understanding by means of introspection, patients might more easily determine self-management strategies that match their current condition, overall character, triggers for depression, and coping style. Secondly, when empowerment develops, the patient's ability to make one's own choices in coping with depression may increase self-management strategies that fit the patient. When strategies are in accordance with personal preferences, this might lead to a long-term deployment. Thirdly, there seems to be a bidirectional relation between the evolvement of experiential knowledge and deployment of self-management strategies. This implies both that self-management strategies are central to the development of experiential knowledge, and that a sustainable deployment of self-management strategies in turn requires increased introspection and empowerment. Finally, it could be assumed that a sustainable deployment of self-management strategies may be enhanced by adjusting self-management strategies to facilitating and impeding factors in patient's unique environment.

Findings in context

In accordance with previous research on experiential knowledge in psychotic disorders and trauma exposure (Boevink, 2012; Burda et al., 2016; De Ridder et al., 2008; Van der Schaaf & Oderwald, 1999), the results of this study highlight that experiential knowledge results from a combination of cognitive and emotional experiences, and patients' practical coping skills in daily life (Boevink, Kroon, van Vugt, Delespaul, & van Os, 2016a; Chambers et al., 2015; De Ridder et al., 2008). The synergetic relationship between the processes in the evolvement of experiential knowledge implies that introspection, empowerment, and factors in the environment must be addressed when developing a personal array of self-management strategies. Stimulating the evolvement of experiential knowledge of an individual patient may be helpful to exceed personal risk factors for neglecting the use of self-management strategies, for example a lack of energy or confusion through the many choices of strategies (DiMatteo et al., 2000; Morgan & Jorm, 2009).

Current results indicate that we need to adopt a broader perspective on coping with depression that exceeds beyond merely referring to self-management strategies (see e.g. Barlow et al., 2002). This means that self-management entails more than specific strategies, i.e. day-to-day tasks an individual undertakes to control or reduce the impact of the condition (Barlow et al., 2002; Clark et al., 1991; Yeung et al., 2009, p. 1). In fact, a broader approach to self-management is expected to interact with introspection and empowerment, and thus the evolvement of experiential knowledge.

The proposition for a broad perspective on coping with depression is echoed in the recovery approach (Leamy et al., 2011). This method suggests that engaging in self-management of a mental disorder needs a holistic view. A holistic approach is characterised by treating the entire person, taking into account the physical, mental, and social factors and needs of a particular patient, not solely focusing on symptoms and diagnoses (Bonney & Stickley, 2008; Jacob, 2015). Thus, personal aspects as well as factors in the wider environment are considered relevant to cope with the disorder (Boevink, 2012; Leamy et al., 2011; Slade, 2009). Treatments for severe psychiatric disorders are increasingly based on the principles of the recovery approach. However, little attention has been paid to this approach in mental health care for depression. In line with the study of Chambers and colleagues (2015), the current research acknowledges the importance and accuracy of the recovery approach in mental health care for depression. Chambers and colleagues (2015) identified facilitating factors for self-management, suggesting "powerful agents" such as hope, confidence and motivation that could help to manage depression. These "powerful agents", as well as a greater emphasis on autonomy and a holistic approach in mental health care, reflect the results of the current study.

Strengths and limitations

A strength of the study is the qualitative design, which allowed participants to give an in-depth description of their experiences and encouraged a holistic perspective on the dynamics of coping with depression. This led to a more inclusive understanding of the complexities of long-term coping with depression. Moreover, involving many stakeholders throughout the research process strengthened the reliability of the results, and allowed to validate the proposed model (see Figure 1) as a fruitful starting point for further research. The current findings overlap with experiential knowledge in other chronic mental illnesses, such as trauma exposure and psychoses. This suggests universal applicable principles in coping with a mental disorder.

However, this research is a first exploration of experiential knowledge in depression. Due to this limitation, the data does not allow to draw definite conclusions about the development of experiential knowledge and its relation to deploying self-management strategies. Furthermore, the back translation of the evolvement of experiential knowledge to individual patients is complex and requires balancing between generalizability of results and the uniqueness of each patient. The small sample size and heterogeneity of patients with chronic and/or recurrent depression makes it difficult to explain the influence of clinical and demographic details on the development of experiential knowledge. Specifically, the generalizability of the findings is limited because the majority of participants were Dutch and highly-educated. Moreover, all participants engaged in mental health care. Participants suggested a different information need and other coping styles in patients with chronic and/or recurrent depression, because of acquired competences in mental health therapies and previous experience in coping with depression. This limits the generalizability of findings to a group of depressive patients with a single depressive episode or starting down a path of recovery. Taken together, more specific research is needed to obtain a deeper understanding of individual clinical details affecting the development of experiential knowledge and deployment of self-management strategies.

Hypotheses can be derived from this study, which lays the groundwork for future research into the evolvement of experiential knowledge and the deployment of self-management strategies in depression. A bigger sample with a wider scope can be used to validate and develop the model of experiential knowledge. To specify the exact course of the development of these concepts, future research can address the following question: *What is needed to benefit from self-management strategies and experiential knowledge on the long-term when suffering from depression?* Including depressive patients who are not successful in the use of self-management can help to fill this knowledge gap. The role of mental health care in facilitating the pathway to experiential knowledge should also be addressed. Furthermore, the use of medication and the course of the depression (chronic, single or recurrent depression) may influence feelings of empowerment and introspection, and thus the evolvement of experiential knowledge and self-management strategies. Therefore, these topics should be discussed in future research on experiential knowledge in depression.

Conclusion

In conclusion, the present study shows that the evolvement of experiential knowledge and the deployment of self-management strategies is a complex cyclical process. The proposed holistic approach towards the relation between the development of experiential knowledge and sustainable deployment of self-management strategies provides a promising perspective on long-term coping with depression, both in research, and in practice.

CHAPTER 3

A Newly Developed Online Peer Support Community for Depression (Depression Connect): Qualitative Study

Smit, D., Vrijsen, J. N., Groeneweg, B., Vellinga-Dings, A., Peelen, J., & Spijker, J. (2021). A Newly Developed Online Peer Support Community for Depression (Depression Connect): Qualitative Study. *Journal of medical Internet research, 23*(7), e25917. doi: 10.2196/25917

Abstract

Background: Internet support groups enable users to provide peer support by exchanging knowledge about and experiences in coping with their illness. Several studies exploring the benefits of internet support groups for depression have found positive effects on recovery-oriented values, including empowerment. However, to date, little attention has been paid to user narratives. This study aims to capture the user perspective on an online peer support community for depression with a focus on the modes of user engagement and the benefits people derive from participation in the forum.

Methods: In this qualitative study, we conducted 15 semistructured interviews with users of Depression Connect (DC), a newly developed online peer support community for individuals with depression. Combining a concept-driven and a data-driven approach, we aimed to gain insight into what users value in our DC platform and whether and how the platform promotes empowerment. We performed a thematic analysis to explore the merits and demerits reported by users by using theoretical concepts widely used in internet support group research. In the subsequent data-driven analysis, we sought to understand the relationship between different styles of user engagement and the participants' experiences with the use of DC. Data analysis consisted of open, axial, and selective coding. To include as diverse perspectives as possible, we opted for purposive sampling. To verify and validate the (interim) results, we included negative cases and performed member checks.

Results: We found participation in DC contributes to a sense of belonging, emotional growth, self-efficacy, and empowerment. "Getting too caught up" was the most frequently reported negative aspect of using DC. The deployment and development of three participation styles (i.e., reading, posting, and responding) affected the perceived benefits of DC-use differentially, where the latter style was central to enhancing empowerment. "Being of value to others" boosted the users' belief in their personal strength. Finally, DC was predominantly used to supplement offline support and care for depression and mainly served as a safe environment where members could freely reflect on their coping mechanisms for depression and exchange and practice coping strategies.

Conclusions: Shedding new light on user engagement processes on which internet support groups rely, we conclude that the online community primarily served as a virtual meeting place to practice (social) skills for deployment in the offline world. It also allowed the members to learn from each other's knowledge and experiences and explore newly gained insights and coping skills.

Introduction

The increased accessibility of the internet, together with the advantages of offline peer support (Lloyd-Evans et al., 2014; Miyamoto & Sono, 2012; Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011), has boosted the development of internet support groups (ISGs). These ISGs enable users to provide peer support by exchanging knowledge about and experiences with coping with a physical or mental illness (Griffiths, Calear, & Banfield, 2009a). Given its recurrent, persistent nature (Hardeveld, Spijker, De Graaf, Nolen, & Beekman, 2010) and the stigma associated with depression (Berger, Wagner, & Baker, 2005), people living with the disorder often search for self-help resources (Barney, Griffiths, Jorm, & Christensen, 2006), and appear to be the most-active users of ISGs, logging in or posting the most frequently (Davison, Pennebaker, & Dickerson, 2000; Griffiths et al., 2009a; Millard & Fintak, 2002).

There has been much focus on the efficacy of ISGs for depression, with previous research examining clinical outcomes and providing compelling but inconclusive evidence for a reduction of depressive symptoms resulting from the engagement in Mental Health ISGs (MHISGs) (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Griffiths et al., 2009a) or depression-specific ISGs (Griffiths, Calear, Banfield, & Tam, 2009b). Additionally, descriptive content analysis studies (Evans, Donelle, & Hume-Loveland, 2012; Feldhege, Moessner, & Bauer, 2020; Griffiths et al., 2009b; Griffiths, Reynolds, & Vassallo, 2015; Moore, Ayers, & Drey, 2016; Nimrod, 2012a; Park & Conway, 2017), user survey studies (Breuer & Barker, 2015; Horgan, McCarthy, & Sweeney, 2013; Nimrod, 2013; Takahashi et al., 2009), and randomized trials or randomized controlled trials (RCTs) (Crisp, Griffiths, Mackinnon, Bennett, & Christensen, 2014; Crisp & Griffiths, 2016; Dean, Potts, & Barker, 2016; Geramita et al., 2018; Goodwin et al., 2018; Morris, Schueller, & Picard, 2015; Rollman et al., 2018; Tomasino et al., 2017) evaluating ISGs for depression generally present positive results on recovery-oriented values, such as personal strength and needs and experiences with (the road to) recovery (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). For example, content analysis studies (Evans et al., 2012; Griffiths et al., 2009b; Griffiths et al., 2015; Moore et al., 2016; Nimrod, 2012a; Park & Conway, 2017) and user survey studies (Breuer & Barker, 2015; Horgan et al., 2013; Nimrod, 2013; Takahashi et al., 2009) collectively indicate that engagement in a depression ISG increases a sense of social and emotional support, and RCTs and other clinical trials suggest short-term improvements in empowerment (Crisp et al., 2014), reappraisal (Morris et al., 2015), and self-efficacy (Goodwin et al., 2018). However, in this body of research, the user perspective has received far less attention (Breuer & Barker, 2015). Such a narrative perspective on associations between processes of user engagement and the perceived value of ISG use can increase our understanding of what users need to benefit from web-based depression platforms.

Recent RCTs on MHISGs indicate that high user engagement quantified in terms of the number of posts (Geramita et al., 2018) or login frequencies (Hensel et al., 2019) is relevant for attaining health gains (Geramita et al., 2018; Hensel et al., 2019). This, however, implies that content analysis studies may be biased. Based on the 1% rule, which postulates that 1% of users contribute around 75% of all ISG posts (Carron-Arthur, Cunningham, & Griffiths, 2014; Van Mierlo, 2014), content analysis studies inevitably evaluate data of small groups of highly engaged users (often referred to as "superusers" or "posters") without considering "lurkers" (users who follow discussions but seldom participate in them by posting; Sun, Rau, & Ma, 2014), whom we prefer to refer to as "readers." Moreover, operationalized in quantitative terms, high user engagement does not capture its qualitative nature (Carron-Arthur, Reynolds, Bennett, Bennett, & Griffiths, 2016). Research into ISG participation styles does allow such a qualitative assessment, with studies revealing very diverse styles across online health communities including ISGs (Carron-Arthur, Ali, Cunningham, & Griffiths, 2015). As to participation styles in MHISGs, the most highly engaged users were typified as "emotionally supportive companions" (Carron-Arthur et al., 2016) and "active help providers" (Nimrod, 2012b; Salem, Bogat, & Reid, 1997), whereas the less active users tended to engage more in topics regarding experiential knowledge, disclosure and informational support (Carron-Arthur et al., 2016). Considering depression-specific ISGs, the profiles identified included "concerned about daily living," "information seekers" (Nimrod, 2013) and "interactive peer support" (Takahashi et al., 2009). Moreover, contrary to quantitative analyses, qualitative characterizations of user engagement (e.g., in terms of participation styles) have not yet explored how these relate to the users' valuation of the benefits and drawbacks of the platforms.

Particularly enhanced empowerment appears to play a key role (Barak, Boniel-Nissim, & Suler, 2008; Bellamy, Schmutte, & Davidson, 2017; Crisp et al., 2014; Melling & Houguet-Pincham, 2011; Nimrod, 2012a) in (depression) ISGs, where gains are assumed to be linked to frequent user engagement (Petrovčič & Petrič, 2014; Risling, Martinez, Young, & Thorp-Froslie, 2017; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009) and possibly to particular participation styles. However, the conceptualization of empowerment lacks clarity (Cerezo, Juvé-Udina, & Delgado-Hito, 2016; Halvorsen et al., 2020; Risling et al., 2017), while also the measures to chart the users' perspectives were very diverse, both in nature and quality (Risling et al., 2017). Based on their analysis of 17 definitions used in the literature, Cerezo, Juvé-Udina, and Delgado-Hito proposed the following narrow definition of empowerment in the context of patients with chronic illnesses such as depression: "An enabling process whereby health care professionals collaborate with patients to help them acquire knowledge and resources and whose outcome is a patient with greater ability to exercise control, manage his/her condition and to make informed decisions" (Cerezo et al., 2016), precluding peer-to-peer empowerment. Empowerment is a multifaceted concept (Halvorsen et al.,

2020) and is considered both process and outcome, with an intrapersonal component ("sense of control"), an interactional element ("critical awareness of the sociopolitical environment") as well as a behavioral aspect ("community involvement") (Miguel, Ornelas, & Maroco, 2015; Zimmerman, 1995). Most studies evaluating effects of ISGs on empowerment focus on the intrapersonal component (Agner & Braun, 2018), whereas social processes in online communities are also likely to foster interactional empowerment (Petrovčič & Petrič, 2014). Taken together, ISG use appears to promote different aspects of empowerment, but it remains unknown whether this is dependent on the nature of user engagement in relation to differential participation styles.

This study is part of a larger research project called "The Power of Depression" in which we seek to build on the recovery approach in mental health (Leamy et al., 2011). In a first exploratory study, we interviewed patients with recurrent and chronic symptoms of depression to gauge their experiential knowledge about coping strategies. The results suggested that gains in experiential knowledge mainly pertained to three intrapersonal factors: introspection, empowerment, and self-management strategies (Smit, Peelen, Vrijsen, & Spijker, 2020). Subsequently, to facilitate the exchange of personal experiences, we developed "Depression Connect" (DC): a closed, moderated platform for online peer support for individuals living with depression. This platform, with a forum as its main feature, was created with the aid of a design thinking methodology following the Human Centered Design Kit (Radboudumc, REshape Center), in close collaboration with potential users currently dealing with depression, their significant others, and health professionals (psychiatrists, therapists, and psychology researchers). We made DC accessible for any person seeking help and support for depression, independent of clinical and demographic characteristics.

We evaluated the self-reported effects of DC on various aspects of empowerment in a quantitative longitudinal user survey (in press). In the qualitative evaluation we present here, we specifically sought to delineate the perceived benefits of DC-participation by evaluating user experiences as a function of their participation styles. Considering the promotion of empowerment key to ISGs (Barak et al., 2008; Bellamy et al., 2017; Crisp et al., 2014; Melling & Houguet-Pincham, 2011; Nimrod, 2012a), as well as social and emotional dimensions that foster empowerment, we expected that DC-participation would affect the users' sense of empowerment differentially depending on the users' mode of engagement.

Methods

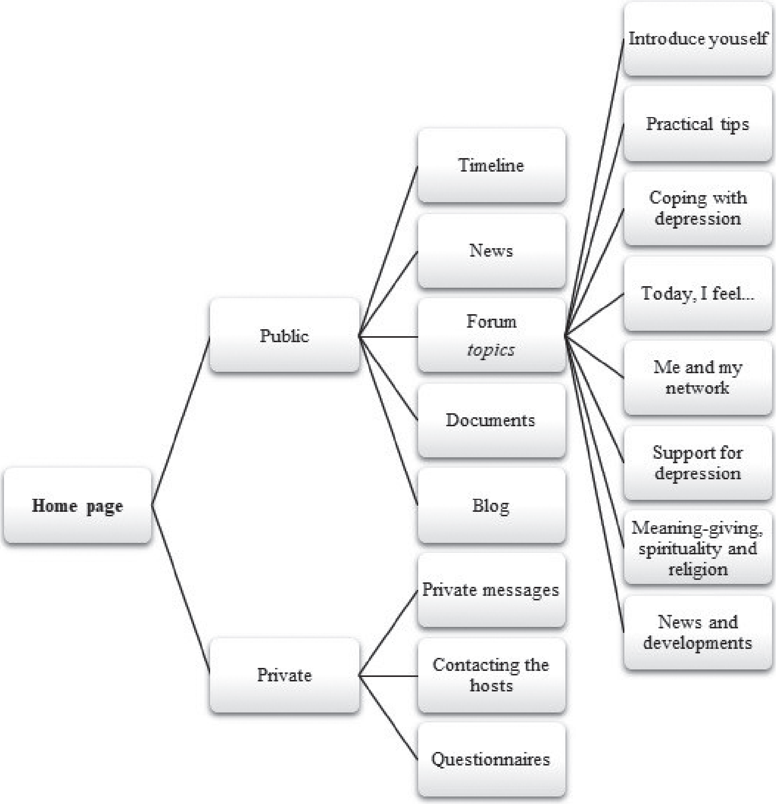
Depression Connect

The online peer support community DC was launched on June 19, 2019. It is a digital platform that offers people with depression the opportunity to (anonymously) read or exchange knowledge about and experiences with coping with depression. It can be accessed via a website hosted by the Dutch Depression Association; the national patient association plays a central role in organizing peer support facilities for this group in the Netherlands. Through their website, any person seeking help for depression has easy access to the DC community. DC was developed and is coordinated by our research group in close collaboration with the Centre of Expertise for Depression, part of the mental health care institution Pro Persona. To recruit a clinical population for our study, we informed members of the patient association, visitors to the website, and patients receiving treatment in a Pro Persona mental health care clinic about DC and our research project through presentations, e-mail, and flyers. We also posted the launch of DC as a news item on various websites associated with mental health care. Although there are other ISGs for depression in the Netherlands, the close collaboration between specialized mental health services and the patient association is one of the main strengths of the DC platform. When moderating and coordinating the DC community, the perspectives of both health professionals and experiential experts are taken into account. Moreover, its structural embedding in the patient and professional organizations fosters topical relevance. For example, by posting news items about depression, both organizations can inspire conversations among users and serve as a reference framework inducing users to revisit the platform regularly.

Next, we outline the login procedure, the guidelines for the moderators, and the functionalities of DC. When accessing the site, general terms and conditions for users, privacy policy, and engagement rules are displayed; this information can also be accessed from the homepage at all times. Any interested user can then sign up for DC-membership. To access the content of the community, members always need to login. When they do so for the first time, they are invited to introduce themselves; this is not mandatory and anonymized profiles are allowed. However, the moderators can always access personal contact details (name and email) to reach members personally, if necessary. Subsequently, new users will see a manual explaining how to use DC. Upon posting the first message, users are welcomed by a member of the DC moderator team. In order to ensure a constructive exchange of peer-to-peer experiences, posts are screened twice a day by one of the 5 moderators. Since the focus groups informing the development of DC expressed a clear need for *peer* support without the involvement of professionals, all moderators are experiential experts. At the end of their (morning or evening) shift, the moderators document peculiarities and the general atmosphere in the forum in a logbook to inform their successor. Moderators only intervene when the content discussed, or a member's conduct, gives rise to conflicts with engagement rules. More specifically, they will act only when an urgent request for support is posted or when they identify suicidal tendencies in posts, and when rules of engagement are violated (e.g., when contributors show disrespect for one another, disclose sensitive information to DC-nonmembers or -outsiders, share information on suicide, or share privacy-sensitive information such as names of doctors). When users exchange misinformation about depression, moderators will refer them to reliable, evidence-based sources of information. As an extra security mechanism, predetermined trigger words, which refer to a crisis situation, will automatically generate a notification in the moderators' mailbox. Launched in mid-2019, the online community attracted an average of 88 new members a month and totaled 1,374 members as of September 24, 2020, when the data for our quantitative user survey study were extracted.

The design of the overall DC website and its forum is straightforward and user friendly, promoting positive user experiences and allowing users to navigate freely (Flavian, Gurrea, & Orus, 2009). Figure 1 depicts the structural organization of the DC platform. Users can create their own topics on the forum, but we also provide eight predetermined topics that we derived from the main themes of experiential knowledge identified in our first study. Besides their contribution to the forum, members can, among other options, read news items and publications about depression (posted by the DC team), post blogs, and send private messages to other DC-users.

Figure 1. *Content and Structure of the Online Peer Support Community Depression Connect*



Study Design

In this qualitative study, semistructured interviews (see Appendix for the interview guide) were conducted with DC-users to explore what the online community had offered them in terms of ways to cope with their current, past, or subclinical depression. We used a hybrid approach (Swain, 2018) combining deductive and inductive reasoning. In the theoretical context of our larger project (Smit et al., 2020), we created a guiding framework (Braun & Clarke, 2006) based on an inventory of experiential knowledge and the relevant literature on empowerment to deduce all relevant factors involved in the broad and complex interplay of depression ISGs (Griffiths et al., 2015). We applied thematic analysis (Braun & Clarke, 2006) to identify, examine, and gain insight into the patterns of predetermined themes. Next, using an inductive, data-driven approach based on the grounded theory (Glaser & Strauss, 2017) and Strauss' exposition of the core principles of qualitative research in social sciences (Strauss, 1987), we kept an open mind to avoid excluding potentially relevant observations. We used specific guidelines to analyze the data; these included open, axial, and selective coding and matrices (Boeije, 2009, pp. 96-118), as well as tree diagrams (Thomas, 2006, pp. 197-198), drawn from the grounded theory. This comparative and iterative approach enabled us to simultaneously analyze and gather new data to further explore and integrate concepts emerging during data collection, which continued until no new main themes emerged.

By combining these top-down and bottom-up approaches, we sought to not only learn what DC-users do and do not appreciate about the platform (charting both the differences and similarities among users) but also further study the role of ISGs in developing experiential knowledge in general and empowerment in particular to (in)validate existing theories. The outcomes would complement our quantitative companion study of the effectiveness of the DC community regarding empowerment (and other aspects). Here, all DC-users were invited to complete questionnaires 3 days after enlisting, with two follow-up assessments at three and six months.

After having evaluated the research protocol in accordance with the Dutch Medical Research (Human Subjects) Act, the local ethics committee (Commissie Mensgebonden Onderzoek Arnhem-Nijmegen) waived ethical approval given the minimal burden to the study participants. All participants were asked to provide written, informed consent prior to the interview following the Declaration of Helsinki.

Study Participants

We posted three calls for participation in our study over a three-month period in the news section of the DC platform. Eight potential participants responded. We sent them an information letter by email, inviting them for a telephone screening. During this call, the researcher provided the candidate with a brief introduction to the study and information on the purpose of the interview, explaining the voluntary nature and confidentiality of their participation. The candidates' demographic and clinical characteristics and patterns of use of the online community were assessed to ensure diversity within the sample. In order to obtain as wide a range of user perspectives as possible, we adopted lenient inclusion and exclusion criteria, resulting in all eight candidates being included, with sufficient differences in characteristics and backgrounds.

After an initial analysis of these first eight interviews to derive the concepts discussed, we used purposive sampling to identify new participants with different profiles and uncover any additional themes. Members with (prior) experience in offline peer communities organized by the Dutch Depression Association were contacted by their regional coordinator, which yielded one participant. At this point, the research sample (n = 9) solely consisted of individuals with recurrent or chronic depression. Therefore, a member who had newly joined DC, introducing herself as having been recently diagnosed with depression, was invited to participate via personal email. We wanted to also include negative cases, that is, DC-users with experiences or perspectives that were likely to deviate from other users and the main theories or evidence on ISG (Maso & Smaling, 1998, p. 75), to potentially provide unexpected findings that might ultimately strengthen the theory. Hence, we recruited two participants who distinguished themselves by their minimal or nonuse of DC after joining the platform. One of these enrolled himself upon our invitation, identifying himself as a DC-member who mainly engaged in other online fora about depression. The second (female) participant was a former Depression Connect-user randomly selected from a contact list of unsubscribed members who was invited via email. Recruited through a fourth and final call for participation on the platform, another three participants were interviewed to achieve data saturation, resulting in a final sample of 15 (former) DC-members.

Table 1 shows the demographics and clinical characteristics of the study participants and the frequency and duration of their use of DC. All participants had received some form of psychological care or treatment at an earlier stage in their lives, with 10 (67%) receiving current and three (20%) awaiting treatment for their depression (including one negative case); two (13%) participants (including one negative case) were not being treated at the time of the interview. Furthermore, 12 of 15 (80%) participants were taking or had taken psychotropic agents for their depression. The majority (11/15, 73%) visited the DC forum regularly, varying from daily to once a week, barring, by definition, the two negative cases and two other members who joined the forum only irregularly.

Table 1. *Demographic and Clinical Characteristics of Study Participants (N = 15) and Their Engagement on The Depression Connect Online Support Community*

Characteristic	Full sample	
	n	%
Gender		
Male	6	40
Female	9	60
Ethnicity		
Caucasian of Dutch descent	15	100
Educational level		
Secondary education (middle or high school)	2	13
Secondary vocational education and training	7	47
Advanced vocational education and training and academic education	6	40
Current mental health care or treatment		
Intake or waiting list	3	20
Ongoing	10	67
Mental-health nurse practitioner (general practice)	3	20
Psychologist or psychotherapist (secondary care)	7	47
None	2	13
Treatment history [a]		
Secondary mental health care (e.g., CBT, psychotherapy)	15	100
Previous psychopharmacological treatment	6	40
Current psychopharmacological treatment	8	53
Never used psychotropic medication	1	7
Number of depressive episodes [b]		
1	1	7
2	1	7
3-5	5	33
Chronic course only (symptoms persisting ≥ 2 years)	7	47
Chronic course in addition to depressive episodes	3	20
Age at depression onset (*years)* [c]		
< 12	1	7
12-18	3	20
19-32	6	40
33-45	4	27
>46	1	7

Characteristic	**Full sample**	
	n	**%**
Duration since onset (*years)* [d]		
0-10	6	40
11-20	2	13
21-30	2	13
31-40	2	13
41-50	3	20
Frequency of using Depression Connect [e]		
Daily	6	40
3 times a week	4	27
Once a week	1	7
Irregular	2	13
Unsubscribed after 1 month of forum use (negative case)	1	7
Inactive (negative case)	1	0.7

Note. Participants were on average 49 years old (*SD* = 11). Abbreviation: CBT = Cognitive Behavioral Therapy.

[a] Including overlap between the categories (e.g., participants using medication and receiving psychotherapy).

[b] Including overlap between the categories (i.e., individuals reporting a chronic course and single depressive episode(s).

[c] Age at depression onset ranged from 8 to 57 years old.

[d] The duration of experiencing depressive episodes or chronic depression ranged from 7 to 45 years.

[e] Excluding the two negative cases, the total duration of DC-use was on average 6.8 months (*SD* = 3.8), with a range of 1.5 - 11 months.

Data Collection

From February 2020 until June 2020, two authors (DS and AD) individually conducted semistructured interviews (*n* = 9 and *n* = 6, respectively) with 15 DC-users (including one former user), lasting from 28.37 to 66.16 minutes (*M* = 48.5, *SD* = 11.25). Both authors have a master's degree in social sciences and are specifically trained and experienced in qualitative research methods. They had created a topic list, building upon the first exploratory study (Smit et al., 2020), the literature, feedback from the project group members (one psychiatrist, three experiential experts on depression, and two senior researchers), and an exploratory interview with a DC-member. As shown in Textbox 1, the following topics guided the interviews: (a) forum use (why, when, and how), (b) DC's benefits and downsides, (c) DC's working mechanisms, and (c) (relationship with) the use of other forms of (in)formal depression support and care. The complete interview guide is available in the Appendix. Based on interim analyses conducted after four and eight interviews, DS and AD reviewed the topic list and incorporated newly identified themes. First, we formulated new questions inquiring into the perceived associations between forum use and personal recovery (coping with depression in daily life), social recovery (effect of social ties and activities), and clinical recovery. Second, to further delineate the effects of DC-use, we added questions about the development and deployment of participation styles. The adjusted topic list was then used for data collection in the successive interviews (Boeije, 2002).

Textbox 1. *Depression Connect Interview Themes and Subthemes*

- Use of the online community
    - Reason(s) for subscribing
    - When, why, and how is Depression Connect used
- Merits and demerits
    - Effect of Depression Connect on coping and living with depression: practical skills, meaning-giving, personal development (self-reflection)
- Working mechanisms
    - Ways in which Depression Connect as an online community and peer support method exerts its effects
- Context: other support or care
    - Ways in which Depression Connect as an online community and peer support method exerts its effects

Data collection took place during the COVID-19 pandemic. The Netherlands was in the early stages of the COVID-19 outbreak when we conducted the first three face-to-face interviews. Consistent with the national measures at the time, the interviewer and participants washed their hands and maintained a physical distance of five feet. When new COVID-19 measures stipulated that social contact be limited, the subsequent 12 interviews were conducted via video calls. All interviews were audio-recorded and transcribed verbatim, omitting any potentially identifying data.

Analysis Strategy

The data were analyzed in ATLAS.ti (version 8.4; Scientific Software Development GmbH). Given our deductive–inductive approach, coding was both concept-driven and open. For the deductive analysis, we prepared a priori thematic codes capturing relevant themes based on the research aim and topic list. To allow findings to emerge from frequent themes without restraints imposed by predetermined concepts (Thomas, 2006), we used open, axial, and selective coding in the inductive analysis (Boeije, 2009, pp. 96-118; Strauss, 1987). To avoid a very narrow perspective, each interview started on an open-coded basis. The data were disassembled into fragments, which were compared with each other and grouped into subject categories. We used a hierarchical category system (e.g., a tree diagram (Boeije, 2009, pp. 124-126) to indicate subordinate and parallel codes and categories. When no new open codes were necessary to cover the data, axial coding was initiated. This more abstract process was used to find connections between and among categories and give coherence to the emerging analysis. Dominant and less important elements in the data were determined to allow selective coding. At that point, the inductive and deductive approaches were combined by harmonizing the category system (based on open and axial coding) with the predetermined concepts (e.g., empowerment) (Smit et al., 2020). Categories were thus organized and integrated to uncover relationships between user engagement, DC appreciation, and the working mechanisms DC-members had proposed. An open network, not specifically indicating causal linkages (Thomas, 2006), was developed in which all the data, including the negative cases, was described and interpreted.

To ensure inter-rater reliability, authors DS and AD met at each stage of the process to discuss codes and themes and resolve any discrepancies. Coding was performed by an independent researcher experienced in qualitative research but not involved in the research project. The small inter-coder variance was resolved by analyzing the coded segments collectively. To increase analytic sensitivity, inconsistently coded blocks were segmented into smaller units and awarded a more specific code, accompanied with a definition that included criteria for the coding of similar segments (O'Connor & Joffe, 2020). Potential interviewer or researcher bias was reduced by having participants check the outcomes to validate and verify the interim and end results. At the first member check after seven interviews, we sent all seven participants a synthesized summary of the data analyzed thus far by email to verify whether the results resonated with their individual experiences. Participants were asked to read, comment, and return the forms. We used nonscientific wording and open questions, leaving room for individual feedback. Six participants returned the forms, and their responses were incorporated into the data set to match this data to the open network (Birt, Scott, Cavers, Campbell, & Walter, 2016). At the second member check after the final interview, we sent all 15 participants a report of the interim results together with an invitation to discuss the report per mail, individual video call, or telephone. Three participants responded, providing feedback via individual video calls. Together, this enabled us to fine-tune the terminology in the interim and final results. Finally, to increase validity and to ensure any new insights into the concepts and results would be taken into account, authors DS and AD maintained a logbook in which they shared personal and theoretical views related to the research and interpretation of the data.

Participants were anonymized and identified by a randomized number (P1, P2, etc), their gender, and age. Below, we present anonymized quotes from participants to illustrate emergent themes.

Results

The interviews provided rich data covering many aspects of engagement on DC and its perceived benefits and drawbacks. We have presented the results in the order in which topics were addressed, starting with the participants' reasons to subscribe, followed by participation styles, and user valuation. We then describe the associations we observed between participation styles and the perceived value of DC. Next, we summarize the negative aspects of DC-use and, finally, discuss the use of DC in relation to face-to-face support, social networks, and mental health care.

Participants' Reasons to Subscribe

Given their persisting symptoms, the participants were at a stage of learning to cope and live with depression in the longer term with a focus on rehabilitation (except for one participant who was first diagnosed with depression six weeks before the interview). A total of 13 (87%) participants described a sense of loneliness or lack of social support as the main reason to engage in the online community. Their primary objective was to look for support in living with depression, which was described as a need for recognition and a genuine understanding from peers:

> *I feel quite lonely in this world. At home, it's difficult for me to speak openly about my problems. When I use the online community, I come into contact with like-minded people. Usually, for tips or a 'pat on the back', things I miss at home.* (P11, male, 55 years)

One participant (negative case) emphasized this finding, while she did experience social support in daily life and unsubscribed from DC.

Participation Styles

The participants used three different participation styles: *reading* messages of peers, *posting* messages to share experiences and ask questions about (coping with) depression, and *responding* to experiences or questions of other users in order to support them. Two female participants did not post any messages because they had issues with sharing personal information. One male user did not post any responses because he struggled empathizing with fellow users.

The data show that the deployment of a specific participation style was dependent on the participants' current mood or state of mind. When feeling low, users mainly read posts or posted messages but did not respond to others' input. Overall, after joining DC, most participants first looked for support and recognition by reading the experiences from peers and posting questions about handling the illness or writing down their own story. Gradually, when their mood had improved or when they felt more at home with or committed to the DC community, participants felt more able to support their peers and started responding to others. A user's participation style could vary within a single session or differ per session, with their forum engagement generally developing from reading only to posting, and eventually responding:

> *At first, I thought people were just nagging a lot in their messages on the forum. I was trying to focus on solving my own problems until I saw that users were helping each other. I realized I could also benefit from their support. I began typing up my personal story. I got positive replies and then also started to respond to others.* (P14, female, 62 years)

User Valuation

Overview. In general, the participants did not report any improvements in depressive symptoms directly associated with the use of DC but often spoke of a process toward accepting the long-term nature of their depression. Hence, the values of DC lay more in the social, emotional, and practical support in learning how to manage the illness:

> *It feels good when I find recognition in the messages of others. It doesn't mean I no longer feel depressed. It just has a positive effect. Also, I get new ideas about treatment options, for example, which will eventually have a positive impact on my symptoms.* (P12, female, 47 years)

The positive effects the 15 users associated with their use of DC can be clustered into four main themes. Ranked according to their importance, these include a sense of belonging, emotional growth, self-efficacy, and empowerment.

Sense of Belonging. Most participants reported that the main benefit of DC-use was the sense of belonging it provided. Recognition, emotional support, and more intrinsic understanding from peers corresponded to their reasons to subscribe, such as loneliness or lack of support in coping with depression:

> *It feels like a warmhearted environment. You feel connected with people through recognition. Other users recognized the feelings I'm struggling with. In turn, I recognized the struggles of others in expressing and sharing their emotions. It all contributed to a natural sense of connectedness, which grew very fast. It feels like I'm in the right place.* (P2, male, 65 years)

The two negative cases did not derive a sense of belonging from the online community because they did not aim for social support: one felt sufficiently supported by face-to-face peer contact and the other, by her offline social network.

Emotional Growth. The data further showed DC to function as a tool for emotional growth: most participants saw DC-use as an incentive to develop and reflect upon personal coping skills and ideas about the (longer-term) management of their depression. Although some topics they read about directly created a sense of recognition for a few participants (which was associated with a sense of belonging), other issues did not directly relate to them but often did trigger them into reflecting on the role the issue might or should play in the management of their depression. This process of personal identification raised the users' (self-)awareness, a necessity for the development of self-knowledge and encouragement for emotional growth. Their narratives indicated that the various processes of self-reflection encouraged them to put their problems into perspective, promoting emotion regulation:

> *Well, when you're sharing experiences you get different viewpoint and more insight, this makes you think more seriously, like: 'Ah, that could be the same for me, or maybe that's a pitfall for me too'. Quiet introspection can help make things more clear and may even be very helpful.* (P7, female, 53 years)

Maintaining online contact with peers did not solely serve as an incentive to reflect upon management and coping strategies. In and of itself, peer contact also helped users develop (better) communication skills. Participation on DC lowered the threshold to talk (i.e., post) about depression; for some participants, the forum also served as a place to practice opening up about depression in face-to-face contacts. Moreover, disclosures tended to invite peers to challenge negative-thinking patterns. In this context, adopting a mild(er) attitude toward oneself was mentioned as an important aspect of information sharing:

> *Maybe, it'll also become easier to speak openly to people in person. I think it's important to practice first, to really get the sense that I'm able to open up before actually doing so in more difficult situations.* (P12, female, 47 years)

Since the two negative cases did not mention emotional growth, we speculate that DC-users need to experience a sense of belonging (which they also said they lacked) before they could benefit emotionally from their contact with peers.

Self-Efficacy. Most participants derived a greater sense of self-efficacy in coping with depression from the online community. Being informed or reminded about (other) coping mechanisms seemed to contribute to their sense of autonomy. Given the longer-term nature of their symptoms, users appreciated tips and experiences about specific treatments, medications, and publications on (coping with) depression the most. About half of the participants (7/15, 47%) also valued more practical advice, using the tips and recommendations about everyday activities as an incentive to (re)engage in these so-called self-management strategies, such as going for a walk or doing relaxation exercises:

> *Sometimes I read messages other users post, like 'I really have to go outside more, but I don't want to', and then, a few hours later, the same user wrote 'Actually, I went for a bike ride'. That is when I think, 'Yeah, I have to go outside too [laughs].' So yes, I have to admit, reading such posts can be an incentive. Also, certain books that people mention can make me curious, prompting me to look for more information. But it depends on how people write about things. When they share information about coping strategies, I 'cherry-pick' the things that suit me most.* (P8, female, 61 years)

Empowerment. Besides increasing their sense of self-efficacy or, more specifically, autonomy, the data suggest that participating in the online community empowered most participants in coming to terms with and manage their depression, with three-fourths of our participants (11/15, 73%) describing DC as a tool to provide meaning to their experiences. They explained that being of value to others living with depression and supporting peers through sharing their own experiences, provided them with a (great) sense of fulfillment:

> *What I try to convey is: Maybe you don't have any perspective now, I understand, I felt the same: 'What am I doing here, on this planet?'. But it will pass, really, it will pass. Even when the response is just a 'thank you', it gives me fulfillment.* (P8, female, 61 years)

After all the problems they were facing because of their depression, the users felt that participating in DC *finally* afforded them a positive and valuable experience. This seems to enhance the belief in their own strength:

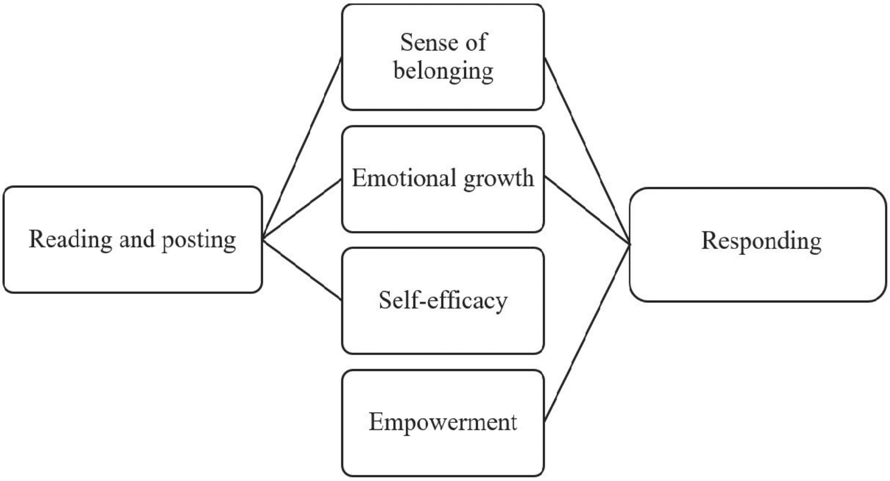
> *You don't get stuck in fear. For example, when you have anxieties or feel depressed, you can feel helpless, you feel lost. When you read messages of your peers saying: 'It will pass', it's like: 'Yes, it will'. This way you encourage yourself to adopt a different attitude toward depression. And, as a consequence, when you get to feel more in balance, you can support others too'.* (P10, male, 62 years)

Consistent with their missing a genuine sense of connectedness with their DC-peers, two participants (both negative cases) did not report deriving fulfillment from being of value to others.

Participation Styles and the Perceived Value of Depression Connect

Overview. To determine how and why DC-users rated the merits of forum participation, we analyzed the interaction and synergy between their participation styles and valuations. The data (schematically depicted in Figure 2) suggest that reading and posting—the styles most users restricted themselves to initially—contribute to a sense of belonging, emotional growth, and self-efficacy, whereas responding, which they later engaged in, was more likely to promote empowerment in addition to a sense of belonging and emotional growth. The elucidation and user quotes below illustrate this relationship.

Figure 2. *Participation Styles and the Perceived value of Depression Connect*



Reading. By reading others' posts, users learned they were not alone in their struggle to learn to cope with negative feelings, recognition of which promoted a sense of belonging:

> *When others wrote about the difficulties at work they experienced on account of their depression, for instance. Suddenly, there was this recognition. A positive sensation because it made me feel like 'Ah, I'm not the only one!'; it's like I read what I could have written myself...It's reassuring. Like in, company in distress makes trouble less.* (P12, female, 47 years)

Furthermore, reading their peers' experiences made users reflect on what the topics meant for them personally, furthering their emotional growth. Finally, the practical tips helped them apply (new) coping skills in their daily lives, which enhanced their sense of self-efficacy.

Posting. In general, posting played a significant and positive role in the appreciation of the forum. Writing down their feelings and struggles in managing their depression often offered users relief, whereas peer recognition and understanding or merely the knowledge that their posts were read by others was of (great) value to DC-users, contributing to their development of a sense of belonging:

> *The online community serves as a 'lifeline' for me. Several times, when I was really struggling, I posted a message on DC [Depression Connect]. Not to get a response, but primarily to be able to express myself by writing down my feelings. I also write for myself, to give words to my emotions. However, writing on the forum differs because I know my posts are being read. Actually, most of the time, people even respond. It's mainly the recognition they articulate that affects me, in a positive sense. Which in itself is quite strange because the recognition of others doesn't essentially change how I feel. But apparently, it works. In the sense that it sort of works as a 'lifeline'. A couple of times when I was doing terrible in the morning and I posted something, it was the responses of others that helped me get through the day.* (P3, male, 48 years)

Moreover, participants explained that sharing their personal story was healing. They managed to organize their thoughts when writing, often reinforcing self-reflection and emotional growth:

> *Writing about my emotions gives me peace of mind. The negative feelings don't disappear completely, but I'm better able to dissociate myself from my problems. What I get from when other users respond to my post is a sense of 'not being alone in this world'. More people are struggling with these same problems, who even try to help others. … It helps me put things into perspective, makes my problems feel less overwhelming.* (P4, male, 31 years)

Finally, posting specific questions about coping with depression often prompted practical tips and other new information, which is likely to have fostered a (greater) sense of self-efficacy.

Responding. Users responding to others' posts derived emotional support and recognition from their peers, which strengthened their sense of belonging. Since providing support or advice entailed having to write down one's thoughts and thus reflect on one's own experiences, this interactive participation style seemed to promote emotional growth. Similar to posting, communicating with peers helped users to better organize and formulate their thoughts:

> *Yes, yes, and I think that's exactly what the online community contributes: learning to think about, learning to reflect on yourself in other, somewhat different contexts. The things you're saying to the other are actually the things that you would like to say to yourself at that moment. Yes, and maybe that's precisely what you do, unconsciously? When you're able to sort of put yourself in the emotional world of another, then you actually feel how good it is to connect with your own emotions. This is when I realize that that is the ultimate goal.* (P2, male, 65 years)

Moreover, responding and helping peers raised the users' sense of fulfillment, which fostered a greater sense of empowerment because they felt they were of value to others.

Negative Aspects of Depression Connect-Use

As to the negative aspects of DC-use, these are best captured under the notion "getting too caught up." Participants explained they could become overwhelmed by the sheer volume of information appearing on the online community, the pressure of having to be continuously available and the stress caused by the concerns they had about the worries of their peers:

> *Well, you can feel overwhelmed by it all. I had mixed feelings. On the one hand, I felt relief because I could share my experiences. But on the other hand – since I visited DC a few times a day, and partly because of all the notifications I received, all the new posts – I thought, 'This is not good. I'm too preoccupied with the forum and worry too much about others right now'.* (P8, female, 61 years)

Users also did not appreciate the forum when their messages appeared to be misinterpreted or when they received unsolicited advice. Although, as mentioned above, half of the participants valued the practical tips on coping with depression, the other half could get frustrated because they felt they were "already aware" of the recommended strategies, or it aggravated their self-criticism because they failed to engage in the suggested activities:

> *In itself, it was good advice, definitely well-intentioned. Also, the content was completely accurate, but I was unable to follow up on it. I felt frustrated because I agreed and knew it was sane advice, it would be the sensible thing to do, but I just couldn't.* (P3, male, 48 years)

Moreover, participants reported that some members confused their own experiences and emotional needs with the personal and unique needs of peers, resulting in useless feedback and a general sense of lack of support.

Use of Depression Connect in Relation to Face-to-Face Support, Social Networks, and Mental Health Care

In general, the participants characterized the use of the online community as being complementary to their real-life peer contacts, their social network, and any professional care or treatment. As they did not feel judged by their DC-peers, the participants referred to the online community as "an emotionally safe context." Not wanting to (over)burden their family and friends with their troubles, initially sharing feelings and receiving peer support online was helpful to some degree:

> *It's about the feelings you share; we're all struggling with depression. It's different from friends of mine who also suffered from depression and are the most approachable people in my network, where I sometimes think, 'I don't want to bother them with my complaints again'. This is much more anonymous. It is voluntary, which is nice because a friend can try to be too supportive and say 'I'll come and see you tomorrow', where I think 'You don't have to come, I only felt like sharing my thoughts because I was having a bad day'. Obviously, things like that don't happen in an online community like this.* (P12, female, 47 years)

At a later stage, DC interactions served as an exercise for self-disclosure in the offline world. Furthermore, anonymous participation, the voluntary nature of DC-engagement, and its 24/7 availability were also mentioned as distinctive positive features compared to seeking or receiving face-to-face support via social networks or from mental health professionals:

> *The fact that you can log on day and night, that's its great strength. As opposed to my psychiatrist, whom I can't email in the middle of the night. I mean, I can, but there's no response.* (P9, female, 42 years)

The overarching principle in the relationship between the use of DC and other forms of support for depression appeared to be the opportunity the forum offered to reflect on and practice the (social) skills the users were trying to master in their daily lives or through psychotherapy. Specifically, discussing topics concerning social interactions and behavioral patterns with peers were considered beneficial:

> *I see the online community as a stepping stone for real-life social interactions with others. I learn by writing down how I should respond, how others might respond. So I'm practicing and learning. Also, I'm learning to become more self-confident so that I can connect better with others.* (P4, male, 31 years)

> *When I'm doing schema therapy with my therapist, difficult issues come to light. I found it helpful to write about these difficulties. It allows me to reflect a bit more on them, and on top of that, I can get some advice.* (P9, female, 42 years)

Discussion

Principal Findings

Central Aim. In light of the promising evidence for depression ISGs (Griffiths et al., 2009b; Hanley, Prescott, & Gomez, 2019; Kingod, Cleal, Wahlberg, & Husted, 2017; Lloyd-Evans et al., 2014), we evaluated the relevance of DC, a newly launched online peer support community based on interviews with a selection of its users. In line with previous research (Crisp et al., 2014; Nimrod, 2012a), we expected that the user narratives would reflect improved empowerment. Given its central role in (online) peer support (Barak et al., 2008; Bellamy et al., 2017; Melling & Houguet-Pincham, 2011) and to clarify the concept (Cerezo et al., 2016; Halvorsen et al., 2020; Risling et al., 2017), we explored the purport of its constituent constructs, and, most importantly, the role different styles of user engagement played in the users' evaluation of DC.

Perceived Value, Participation Styles and a Central Drawback of Depression Connect-Use. Participation in the online community engendered a sense of belonging and promoted the users' emotional growth and sense of self-efficacy and empowerment, with self-efficacy and empowerment boosting their sense of autonomy. Where improved empowerment mainly pertained to interactional and behavioral constructs (Miguel et al., 2015; Zimmerman, 1995), such as meaning-giving and being of value to peers through providing support, gains in self-efficacy mostly concerned intrapersonal constructs such as being informed about treatments. With respect to modes of user engagement, three styles were identified, starting with reading only, evolving into posting, and culminating in responding. Individually and together, these participation styles related differentially to the users' (overall positive) appreciation of the platform. As a truly interactive engagement style, responding played a key role in empowering users; being valuable to others boosted their belief in their own abilities (personal strength). Primarily, the participants used the forum to explore and try (new) coping and social skills for later use in their real lives. The central drawback of DC-use was that some users had become too involved in the community, getting overwhelmed by the continuous supply of posts and messages and their empathy for their fellow users. Finally, they noted that the DC community had provided them with an emotionally safe context to reach out to others in addition to their seeking or receiving face-to-face support and professional care.

Empowerment. One definition of empowerment in the context of this study reads "health care professionals collaborating with patients to help them acquire knowledge and resources" (Cerezo et al., 2016), which implies that it requires an inherently unequal relationship—one between knowledgeable health professionals and uninformed patients—to acquire knowledge and skills in managing a condition. Due to this paternalistic interpretation, the construct of empowerment is being criticized, as it contradicts the collaborative nature of the process (Halvorsen et al., 2020).

Together with earlier positive findings on ISGs (Breuer & Barker, 2015; Griffiths et al., 2015; Nimrod, 2013), our results suggest that offline and online peer communities for depression can be quite helpful for users to learn about and try new management and coping techniques. The reciprocal and "same-level" character of peer support defies the paternalistic notion of empowerment (Halvorsen et al., 2020). In terms of empowering patients, interactions with peers may even supplement professional care given that sharing experiential knowledge is not part of the therapeutic relationship.

Considering empowerment is a process rather than a mere outcome (Cerezo et al., 2016; Miguel et al., 2015), we found that use of the DC platform specifically supported processes such as helping others (van Uden-Kraan et al., 2008) and meaning-giving. Peer contacts, and particularly sharing experiential knowledge to support others, fostered an external focus, consistent with the assumption that ISGs promote interactional empowerment. As an integral part of the process toward empowerment (Cerezo et al., 2016), we found that self-efficacy was mainly boosted by intrapersonal processes (i.e., gaining personalized information on depression and coping skills) mirroring intrapersonal empowerment. Accordingly, we presume that participating in ISGs helps advance both intrapersonal and interpersonal or interactional empowerment.

Findings in Context

Development and Variation in User Engagement. The benefits the DC-users we interviewed derived from the forum are consistent with findings of other studies: informational and emotional support (Evans et al., 2012; Griffiths et al., 2009b; Griffiths et al., 2015; Moore et al., 2016; Nimrod, 2012a; Park & Conway, 2017), social companionship (Goodwin et al., 2018; Griffiths et al., 2009b), and empowerment (Crisp et al., 2014; Nimrod, 2012a). Exploring which mechanisms drive ISGs and DC in particular, we compared styles of user engagement with the users' judgments. Although the three participation styles we identified (reading, posting, and responding) all had their own merits, the users' narratives revealed differential patterns in their online behavior. As alluded to in the introduction, previous ISG studies generally distinguished "lurkers" (i.e., readers) and "posters," that is, users with fixed behavior patterns (van Uden-Kraan et al., 2008). However, our results suggest that due to the cyclical and erratic nature of depression participation styles tend to evolve and fluctuate. According to most participants, the autonomy in choosing how they engaged in DC was a core advantage of online peer support, distinguishing it from other forms of offline peer support or formal care. When faced with (recurrent) depression, people often feel compelled to keep functioning well in daily life, being a good spouse, mother or father, employee, friend, or even patient (Smit et al., 2020). When seeking support online, they do not feel this pressure and can let themselves be guided by their current needs. Whether they translate this behavior and positive experience to everyday life remains unknown.

Moreover, the development of and variations in participation styles over time contributed to user satisfaction. After a passive start, users gained more confidence from reading others' posts and responses and became more (inter)active themselves, making the shift from reading only to asking for help, sharing experiences, and finally helping others. Posting and responding brought gratification, boosting the way they thought about themselves, adding to their self-confidence, which Schwartz termed the "response shift effect in peer support" (Schwartz & Sendor, 1999). Nevertheless, future investigations should confirm whether accessible online communities like DC facilitate the transfer of learned skills to daily life.

Participation Styles and Perceived Value of Online Peer Support. In addition to the development of and flexibility in user engagement over time, our data suggest a direct association between participation styles and the perceived value of DC as an online community, which expands the findings on depression ISG research (Nimrod, 2013). We found that the hypothesized relations between participation modes and ISG appreciation are similar to processes and associations observed in mental health care. Thus, the relationship between responders and enhanced empowerment resembles the benefits people derive from the so-called "helper-role" (Schwartz & Sendor, 1999) during group sessions or peer support meetings. The positive effects of helping others by responding to their narratives, such as feeling useful (Solomon, 2004; Watson, 2017), promotes empowerment, as is also reflected by the growing (self-)confidence DC-users reported when they began responding to peers. The observed association between posting and emotional growth or emotion regulation (i.e., increasing self-knowledge through reflection on coping processes) echoes the role of expressive writing in reducing psychological distress (Dean et al., 2016; Frattaroli, 2006). By posting, simply another form of expressive writing, DC-users found themselves learning to express and control their emotions better. In sum, we show that ISG members use passive, active or interactive styles of engagement to seek and derive different types of support from online peer communities, dependent on their personal needs over time.

Practical Implications of ISG Use

In their systematic review, Leamy and colleagues (2011) pose that in the context of recovery-oriented mental health care, coping with depression exceeds self-management and clinical recovery. They propose important themes for personal recovery, including connectedness and empowerment (Leamy et al., 2011), which correspond to the main advantages mentioned by DC-users in our study. Hence, we posit that participation in an ISG may facilitate and possibly accelerate recovery (i.e., improved symptom management), with users finding their own paths.

Importantly, we found that the DC platform was mainly used in addition to professional psychological or psychopharmacological care, experiences with which were exchanged, with peers offering the participants different, experiential perspectives on (coping with) depression. Since ISGs offer its members a more holistic approach to their mental health issues and associated problems, health professionals may consider recommending them to (some of) their clients to complement ongoing therapy or as a form of informal follow-up care after therapy discontinuation. As a matter, of course, they are advised to inform themselves and their clients of the potential adverse events associated with online fora (Easton et al., 2017).

Limitations

DC-users we interviewed may not be representative of all DC-members; apart from the two negative cases, most participants were probably among the more frequent users because they were the more likely to come across the invitation for participation we posted. Furthermore, because the interviews were conducted during the COVID-19 pandemic when face-to-face contact was restricted, the importance of online types of support for depression increased, potentially causing the results to be biased in a positive direction.

The high accessibility (i.e., free and ease of use) of the DC platform, the encouraging but nondirective role of its moderators, and its structural embedding in both a patient and mental health organization may have fostered social and interactive processes (e.g., connectedness and support) that may not be representative of other ISGs that are less closely monitored (Young, 2013). Moreover, since DC is a Dutch-language forum and all participants were Dutch, we do not know whether our findings can be generalized to ISGs in other countries. It is possible that Dutch users attribute a greater value to (online) peer support because such services are not embedded in regular depression care in contrast to other countries, such as Germany (Matzat, 2002). Finally, the benefits our participants claimed to derive from the use of DC largely reflect short-term gains, as the duration of their forum participation varied from 1.5 to 11 months at the time of data analysis.

Future Research

In a quantitative parallel study, we evaluated the effects of DC-use on empowerment (primary outcome measure) after three and six months. Further longitudinal research should be aimed at the longer-term beneficial and adverse effects of participation in ISGs.

A mixed-method effectiveness study should address the complexity and potential of peer support interventions. The method can yield rich and comprehensive data and thus provide a more holistic view on how people cope with depression. In this context, examining the perceived level of social support in daily life in relation to user statistics of online peer support services will be informative. Finally, a key challenge is to determine whether skills learned from peers in online networks also contribute to mental health recovery in the offline world (Naslund, Aschbrenner, Marsch, & Bartels, 2016).

Conclusion

Users of DC considered the online peer support community an accessible and valuable tool for learning to cope (better) with their depression. Seeking to understand the working mechanisms of ISGs, we found that the greater majority of the study participants benefited from the freedom and flexibility DC offered, allowing them to employ passive, active, and interactive styles of user engagement depending on their current mood and needs. Most found the forum, monitored by experienced peers, a safe environment to practice social and coping skills for later deployment in the offline world, supplementing (in)formal care. We found that besides promoting intrapersonal empowerment, DC also fostered interactional empowerment. Provided platforms are closely monitored and used to complement or follow-up formal care, and pending further investigations, we suggest that online peer support may be recommended as a safe context for exchanging knowledge and experiences on how to cope with depression and practice newly gained insights and skills.

CHAPTER 4

User Engagement Within the Online Peer Support Community "Depression Connect" and Recovery-related Changes in Empowerment: a Longitudinal User Survey

Smit, D., Vrijsen, J. N., Broekman, T., Groeneweg, B., & Spijker, J. (2022).
User Engagement within the Online Peer Support Community 'Depression Connect' and Recovery-related Changes in Empowerment: a Longitudinal User Survey.
JMIR Formative Research (in press). doi: 10.2196/39912

Abstract

Background: The chronic nature of depression and limited availability of evidence-based treatments emphasize the need for complementary recovery-oriented services, such as peer support interventions (PSIs). Peer support is associated with positive effects on clinical and personal recovery from mental illness, but little is known about the processes of engagement that foster change, and studies targeting individuals with depression are limited. This study evaluates whether the level of user engagement, assessed on several dimensions, in an online peer support community for individuals with depression promotes empowerment and the use of self-management strategies, and reduces symptom severity, and disability.

Methods: In a longitudinal survey conducted from June 2019 to September 2020 we analyzed the data of users of Depression Connect, an online peer support community hosted by the Dutch Patient Association for Depression and mental health care institution Pro Persona on measures of empowerment, self-management, depression, and disability. Of the 301 respondents, 49 completed the survey again after three months and 74 after six months. Analysis of three parameters (i.e., total time spend on the platform, number of page views, and number of posts) derived from their data logs yielded four engagement profiles. Linear mixed models were fitted to determine whether outcomes had significantly changed over time and significantly differed for the various profiles.

Results: Baseline engagement with the online peer support community was *very low* (177/301, 59%) or *low* (87/301, 29%) for the majority of the participants, with few showing *medium* (30/301, 10%) or *high* engagement patterns (7/301, 2%), while user profiles did not differ regarding demographic and clinical characteristics. Empowerment, self-management, depressive symptoms, and disability improved over time but none were associated with the intensity or nature of user engagement.

Conclusions: With the great majority of Depression Connect-members showing very-low-to-low engagement and only few being identified as high-engaged users, it is likely that this flexibility in usage frequency is what provides value to online PSI users. In other more formal supportive environments for depression a certain level of engagement is predetermined either by their organizational or by their societal context, at Depression Connect users can adapt the intensity and nature of their engagement to their current needs on their personal road to recovery. This study adds to the current knowledge base on user engagement for PSIs since previously conducted studies targeting depression with online format, focused on active users, precluding passive and flexible engagement. Future studies should explore the content and quality of the interactions in online PSIs to identify optimal user engagement as a function of current, self-reported clinical parameters and reasons to engage in the PSI.

Introduction

Peer support for recovery in depression

It is estimated that around 280 to 320 million people worldwide are coping with depression (Üstün, Ayuso-Mateos, Chatterji, Mathers, & Murray, 2004; Vos et al., 2020; WHO, 2017). Yet, the availability of evidence-based mental health care, such as psychotherapy and psychopharmacology (Cuijpers et al., 2020), is insufficient due to high costs, and a lack of skilled clinicians (Patel et al., 2018). Moreover, the high recurrence rates reported underline the chronic nature of the illness (Mueller et al., 1999). The fact that so many individuals live long-term with (recurrent and persistent) depression, emphasizes the need for recovery-oriented services that focus on emotional support and resilience rather than on symptom reduction (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Peer support interventions (PSIs) could provide such a source of support on the longer road to recovery (WHO, 2021), complementing professional treatment (Davidson, 2005a; Jacob, 2015) for depression (Bryan & Arkowitz, 2015; Griffiths, Calear, Banfield, & Tam, 2009b; Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011). In particular PSIs with online formats meet the need for accessible and low-cost interventions (WHO, 2021), and by offering the possibility of anonymous engagement help circumvent the stigmatization associated with depression (Houston, Cooper, & Ford, 2002).

Principally, peer support entails giving and receiving help by exchanging personal experiences (Mead, Hilton, & Curtis, 2001), where the central themes are “respect, shared responsibility, and mutual agreement of what is helpful” (Mead, 2003 p. 1). However, owing to the great variety of intervention types, deployment across different user groups and service delivery settings, there are multiple definitions of peer support (Chinman et al., 2014; Shalaby & Agyapong, 2020). In light of this heterogeneity, it is difficult to systematically disentangle the principal benefits of these systems.

The effectiveness of peer support

Our research group recently conducted a comprehensive meta-analysis of 28 randomized controlled trials (RCTs) to assess the efficacy of PSIs across a wide range of mental disorders and intervention types. Compared to control conditions, the PSIs we reviewed were associated with modest but significant positive effects on clinical symptoms and personal recovery (e.g., promoting hope; Leamy et al., 2011) in individuals with mental illness (Smit et al., 2022). Specifically for individuals with serious mental illness, including major depressive disorders, peer support was associated with superior outcomes across clinical, personal, and also functional recovery variables (e.g., quality of life and social support) relative to control conditions.

It needs to be noted that only a limited number of trials in our meta-analysis focused on *online* PSIs targeting *depression*. Nevertheless, the results of these few trials were promising. Specifically, findings of the RCT conducted by Griffiths and colleagues (2012) suggested that engaging in a moderated depression internet support group may be clinically effective (i.e., reducing depressive symptoms) in the long-term (Griffiths et al., 2012) with potential short-term improvements for empowerment as presented in a companion paper of Crisp and colleagues (2014) reporting on the same trial (Crisp, Griffiths, Mackinnon, Bennett, & Christensen, 2014; Griffiths., et al., 2012). In addition to this quantitative evidence from a single trial for a depression PSI, systematic reviews that are more descriptive in nature (i.e., a narrative synthesis for the efficacy of PSIs, not including a meta-analysis that systematically assesses the results of previously conducted studies), emphasize the potential of *online* health-related PSIs in general (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Fortuna et al., 2020; Kingod, Cleal, Wahlberg, & Husted, 2017), and that of those specifically addressing depression (Griffiths, Calear, & Banfield, 2009a; Griffiths et al., 2009b).

The results of a broad systematic review (Winsper et al., 2020), may help us understand better how these positive outcomes in PSIs may develop. Winsper and colleagues (2020) identified four common processes fostering change for recovery across 309 studies on recovery-oriented interventions for mental illness: (a) providing information and skills; (b) promoting a working alliance; (c) role modelling for individual recovery; and (d) increasing choice and opportunities (Winsper et al., 2020). These processes may best be initiated within non-stigmatized recovery-focused contexts, such as peer support where psychosocial processes of sharing lived experiences, emotional honesty, strengths-focused social and practical support, and the helper-role are important processes for mental health recovery (Watson, 2017). Results of our qualitative evaluation study for users of the online peer support community DC fit with these processes (e.g., sense of belonging, self-efficacy, and empowerment; Smit et al., 2021).

User engagement within online peer support interventions

However, it remains unclear which PSI engagement processes are associated with change. In particular for online PSIs, a high level of user engagement is considered a crucial factor for recovery (Fortuna et al., 2020; Geramita et al., 2018; Hensel et al., 2019). A systematic review of online health communities showed that several multidimensional factors are relevant when defining user engagement, such as metrics characterizing user networks (e.g., the number of people a user has interacted with), content (e.g., the nature of posts), and activity (e.g., the number of posts and log-in times) (Carron-Arthur, Ali, Cunningham, & Griffiths, 2015). Use of online PSIs is mainly operationalized in terms of frequency of use (Carron-Arthur et al., 2015), where the dichotomy between “lurkers” (i.e., passive users, generally a substantial group, whose use is mainly restricted to reading others’ posts) and “posters” (i.e., active users, generally only 1% of users (Carron-Arthur, Cunningham, & Griffiths, 2014; Fullwood et al., 2019; Petrovčič & Petrič, 2014; Van Mierlo, 2014; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008) is widely used. To accurately reflect the larger group of passive users, we need a more nuanced characterization of their engagement (Carron-Arthur et al., 2015; Fullwood et al., 2019). Such parameters of non-active engagement are particularly relevant for PSIs for depression since passive behavior is associated with the condition (Patten, 1999). We therefore conducted a qualitative evaluation among users of Depression Connect (DC) (Depression Connect, 2019; Smit et al., 2021), our self-developed online peer support community for individuals struggling with depression. Our *qualitative* analysis of user experiences of DC revealed three successive participation styles (i.e., reading, posting, and responding), that individually and together coincided with an increased sense of belonging, emotional growth, self-efficacy, and empowerment (Smit et al., 2021). In this second *quantitative* evaluation of DC, we studied engagement patterns as a possible mechanism for recovery more closely by assessing multiple metrics to define engagement as comprehensively as possible (Carron-Arthur et al., 2015).

For the current study and based on user data logs for DC, we included three parameters to operationalize the intensity level of user engagement: the number of posts, the number of page views, and the total time spent on DC. Including both active and passive user modes, it is important to acknowledge that high user engagement is not limited to active users, referring to users that posted (a substantial number of) messages on the platform. In user data logs for DC, it was not possible to distinguish the two active participation styles posting and responding that followed from our qualitative evaluation. To include passively engaged users to our sample, we assessed the number of page views and the total time spent on DC per individual user. However, since users may have been active through sharing posts when viewing various pages on the platform during their time spent on DC, these parameters include, but are not limited to, the passive user mode of reading. Together, our operationalization of user engagement implies that both active users who posted and passive users who spent considerable time on DC and viewed many pages could be categorized as highly engaged users.

Recovery-oriented outcomes

In recent years, peer support studies reported on personal recovery to complement clinical recovery outcomes, with a particular focus on the benefits of (online) PSIs for *empowerment*, an important feature in the process of personal recovery that individuals can (learn to) develop to enable them to live a (more) meaningful life are frequently addressed (Leamy et al., 2011; Slade et al., 2012; WHO, 2013). Although inconclusive, findings were promising (Burke, Pyle, Machin, Varese, & Morrison, 2019; Crisp et al., 2014; Lloyd-Evans et al., 2014; Lyons, Cooper, & Lloyd-Evans, 2021; White et al., 2020). Within online communities, empowerment refers to enabling processes including "becoming better informed, receiving and giving emotional support by sharing relatable experiences of living with the diagnosis, helping others, and networking" (Johansson, Islind, Lindroth, Angenete, & Gellerstedt, 2021, p. 11). Developing and exploiting self-management strategies can be seen as an active component of empowerment (Cerezo, Juvé-Udina, & Delgado-Hito, 2016; Risling, Martinez, Young, & Thorp-Froslie, 2017) and many comprise individual skills "to monitor one's condition and to affect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life" (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178). However, as yet, self-management has not been systematically examined as an individual outcome in peer support studies (Houle, Gascon-Depatie, Bélanger-Dumontier, & Cardinal, 2013). The same holds for general well-being (i.e., functional recovery, including social functioning, and quality of life) (Bryan & Arkowitz, 2015; Burke et al., 2019; Chien, Clifton, Zhao, & Lui, 2019; Fuhr et al., 2014; Huang et al., 2020; Lloyd-Evans et al., 2014; Lyons et al., 2021; White et al., 2020), while both are important parameters for determining the usefulness of recovery-oriented PSIs. As findings of our meta-analysis showed that PSIs may also be effective in terms of clinical recovery (i.e., symptom reduction), in particular for individuals with serious mental illness, including major depressive disorder, we will also look whether our online peer support platform helps improve depressive symptoms.

Objectives

Taken together, in this longitudinal user survey we attempt at adding to the current literature on online peer support in several ways. First, we examine both personal (i.e., empowerment, self-management), functional (i.e., well-being), and clinical (depressive symptoms) recovery parameters among users of Depression Connect. Furthermore, we explore patterns for user engagement comprehensively, including parameters reflecting both the intensity and nature of DC-use. Following the results of a systematic review of user engagement (Carron-Arthur et al., 2015), we clustered user engagement based on the number of posts, page views, and total time spent on Depression Connect. We aimed to learn whether these user engagement profiles during a 6-month interval were related to changes in empowerment. We expected that high-frequent -including active (i.e., number of posts) and passive (i.e., number of page views, total time spent) -user engagement would contribute to more improvement in empowerment from baseline to three and six months compared to lower user engagement frequency. Secondary, we explored the use of self-management strategies and changes in depressive symptoms, the level of functioning and disability over time.

Methods

Design

For this longitudinal study, users of DC, our online peer support community for depression, completed an online survey at three time points between 19 June 2019 and 24 September 2020.

Ethical Approval

After evaluation, the local ethics committee [Commissie Mensgebonden Onderzoek Arnhem-Nijmegen] determined no ethical approval was required given the minimal burden to the study participants. The users gave their passive consent to log and analyze their user data.

Depression Connect

Launched 19 June 2019, DC was co-created with experiential experts, caregivers, and health professionals (therapists, psychiatrists, and psychology researchers) affiliated with the Dutch patient association for depression (The Depression Association), the Centre of Expertise for Depression as part of the Pro Persona institute for mental health care, and the Radboud University Medical Centre. DC was developed to facilitate the exchange of personal experiences in coping with depression among peers. The online platform is easily and (if so preferred) anonymously accessible for anyone dealing with depression. Potential users are not screened for depressive symptoms or other clinical characteristics before they can enter the community. Although no professionals are involved in DC, its moderators, who are all experiential experts, are able to consult a psychiatrist and psychology researchers of our team when feedback is needed. To ensure a constructive and supportive online atmosphere, DC-moderators screen all new posts on a daily basis. They also generate new content or boost users' activity of the platform, for instance by posting news items or different viewpoints on coping strategies. On a monthly basis, the DC team welcomed an average of 90 new members. DC-members can start a new discussion topic, or join an existing topic created by other users or provided by the research team. At DC's launch, we created eight forum topics that referred to the main themes of experiential knowledge in depression, which we identified in our qualitative interview study (Smit et al., 2021). Widely used topics are on how to cope with symptoms of depression (e.g., concentration problems) and treatment options for depression (e.g., medication and mental health care). In addition to reading and posting messages at the forum section of the community, users can read news items (posted by DC's team) and read or post blogs. There is also a function to send private messages to other DC-users. More details about DC's development, functionalities and monitoring procedures have been presented in our parallel qualitative evaluation of DC (Smit et al., 2021).

Participants and procedure

Simultaneously with the launch, all individuals who registered with DC were invited to participate in our study. There were no strict conditions to participate in the study regarding demographic and clinical characteristics, neither for minimum or maximum level of engagement at DC. All new DC-members, and thus potential study participants, received an e-mail to welcome them to the community, including information about our quantitative evaluation study and a link to the survey. An email address of the research team was also displayed to give users the opportunity to ask questions about study participation. Participation was on a voluntary basis without any financial or other compensation. Interested users were invited to complete the online survey one or two days after registering, and at three and six months after joining DC. Of the 1,374 new members who joined DC during the recruitment period, 317 users (23.1%) completed the baseline survey. Sixteen participants subsequently deleted their account including their user data logs, leaving the data of 301 participants (21.9%) for the final sample. The datasets of participants having completed a baseline assessment only (179/301, 59.5%) were not included in the outcome analyses.

Measurements

Participants completed the following measures at baseline, and at three months and six months after joining DC.

Demographic and clinical characteristics. At the baseline assessment, the participants were requested to list their age, gender, and level of education and at all three time points we asked participants if they received current treatment (referring to any form of mental health care), used antidepressant medications, and whether they were experiencing a depressive episode at the time of the assessment. These variables were assessed by self-report, we did not use a validated symptom screening measure.

User engagement. Participants' engagement in DC was determined by analyzing user data logs, which were encrypted and provided by the website host (Digitalepoli, 2022). In line with the most widely used metrics to categorize user engagement in online health communities (Carron-Arthur et al., 2015; Carron-Arthur et al., 2014), we computed the following three parameters after three and six months of DC-use: (1) total time spent on DC, (2) the number of page views, and (3) the number of posts entered on DC. We did not take into account the online activities related to the completion of the surveys.

Outcomes

Empowerment. To gauge changes in empowerment, we used the Netherlands Empowerment List (NEL) (Boevink, Kroon, & Giesen, 2008), that consists of 40 questions covering the following six subscales: Social Support, Professional Help, Connectedness, Confidence and Purpose, Self-Management, and Caring Community. Items were to be answered on a 5-point Likert scale ranging from 0 (strongly disagree) to 4 (strongly agree), with a not applicable answer option for the Professional Help subscale. We calculated a total empowerment score by summing and averaging all completed items (range 0-4). Items of the Professional Help subscale that were scored as not applicable were not included in this calculation. Higher scores reflect higher levels of empowerment. Both previous research (Boevink, Kroon, Delespaul, & Van Os, 2016b) and this study achieved high reliability for the total score ($\alpha = .93$).

Self-Management. The use of self-management strategies was evaluated with the Dutch Assessment of Self-management in Anxiety and Depression questionnaire (ASAD) (Krijnen-de Bruin et al., 2021; Zoun et al., 2016). The ASAD considers 45 self-management strategies presented in an equal number of statements. Respondents are asked whether and to what extent they employed the strategy referred to (e.g., “Keep focused on the present, and stop myself from looking too far ahead”). Each item is rated on a 5-point Likert scale, ranging from 0 (not at all) to 4 (very much). We used a total score (range 0-180) in our analyses. The higher the score, the higher the use of the self-management strategies. The reliability in the current study was high ($\alpha = .92$).[1]

Depressive symptoms. Depression severity was assessed using the Dutch version of the Beck Depression Inventory-II (BDI-II) (Beck, Steer, & Brown, 1996), which consists of 21 questions, with each answer scored on a scale from 0-3. The total score ranges between 0-63, with higher scores reflecting more severe depressive symptoms. Specifically, a score between 0-13 indicates minimal symptoms, a score between 14-19 a mild depression, a score between 20-28 a moderate to severe depression, and the highest category with scores between 29-63 a severe depression (von Glischinski, von Brachel, & Hirschfeld, 2019). The BDI-II has good psychometric properties (Wang & Gorenstein, 2013). In this study, reliability of the total score was high ($\alpha = .91$).

Functioning and disability. We assessed individual functioning and disability with the Dutch 36-item version of the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) (Üstün, Kostanjsek, Chatterji, & Rehm, 2010). Six domains (i.e. Cognition, Mobility, Self-Care, Getting Along, Life Activities, and Participation) are evaluated with a total of 36 items to be rated on a 5-point Likert scale, ranging from 0 (no effort at all) to 4 (much effort), where higher scores indicate more disability. The WHODAS 2.0 36 item-version is a valid and reliable self-report instrument, with good psychometric properties irrespective of population type (Federici, Bracalenti, Meloni, & Luciano, 2017), which was reflected by the high reliability for the total score in our study ($\alpha = .92$).

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[1] Previous research only examined psychometric properties for the ASAD-Short Form, showing high levels of internal consistency (Cronbach’s alpha > 0.75) for the total questionnaire as well as its subscales (ICC > 0.75) (Krijnen-de Bruin et al., 2021)

Statistical Analysis

Outcomes. Data analyses were conducted using IBM SPSS Statistics Version 28 and R version 4.1.1 (Team R., 2021) using R Studio 2021.09.0+351. Longitudinal modeling was performed using the R lme4 package (Bates, Maechler, Bolker, & Walker, 2021). To determine whether outcomes had significantly changed over time, and significantly differed between user engagement profiles, linear mixed models were fitted with the respective outcomes as dependent variables. In the model, the Restricted Maximum Likelihood Estimation (REML) calculates parameter estimates. Since multiple imputation is not deemed necessary, we did not conduct a missing data analysis a priori (Twisk et al., 2020). We specified a linear mixed model regression with fixed effects: the actual day of assessment (day), engagement profiles, and the interaction effect between engagement profile and day of assessment. The baseline value (day = 0) of the outcome variable was included as a covariate, and random slopes for the within-subject day effect were included.

Estimated marginal means and within-group effect sizes were calculated with the Emmeans package in R (Lenth, 2022). We calculated the magnitude of change between the baseline assessment (day = 0) and assessment 3 (day = 186), reported as the effect size, Cohen's *d* (Cohen, 2013). For the effect size calculation we needed an estimate of the standard deviation (SD) of the intercept. In the model including the baseline value of the outcome variable as a covariate the estimate of the intercept's SD was naturally almost zero. Therefore, we used the model without this covariate to obtain an estimation of the SD of the intercept.

Engagement profiles. We used cluster analysis to identify subgroups of participants that shared similarities in their forum use patterns. Next, we performed a K-Medoids cluster analysis with the R package Cluster (Maechler, Rousseeuw, Struyf, & Hubert, 2021), using the Partitioning Around Medoids (PAM) algorithm, a more robust version of the K-means algorithm, that, instead of averages of distances between points in the sample, uses actual data as the center of a cluster. For each subject (1) session duration; (2) number of page views; and (3) number of posts were computed for the first three months and the last three months, excluding the sessions in which the questionnaires were filled out. Because of extreme skewness in these six indices, we took their square roots and transformed these to Z-scores for the cluster algorithm. Although the Tibs2001SEmax gap criterion (Maechler et al., 2021) found an optimum of seven clusters, the number of participants was very small in the high engagement clusters (n = 3 and n = 4), which is why we opted for a 4-cluster solution in which the high engagement cluster contained seven participants.

Results

Data preparation

Of the 301 DC-users who had provided their consent and completed the baseline measurement, 179 individuals did not complete the survey at the three and six-month time-points. In all, 48 DC-users completed the three-month and 74 participants the six-month survey. There was no missing data for the four main outcome measures at any of the three time points. For age and current depression we noted two and six missing variables, respectively. A total of 496 observations for 301 participants were entered into the mixed modeling analyses.

Baseline characteristics of participants

The participants' demographic and clinical characteristics as well as the means and SDs for the outcome variables at baseline are shown in Table 1. Our sample of 301 DC-users included individuals with self-reported depression and a mean age of 50.2 years (*SD* = 13.12), 66.1% of them were female and the majority of the respondents (85.4%) had completed some form of secondary education or training. Well over half of the respondents (166/301, 55.1%) reported having severe depressive symptoms (mean BDI score of 38.7) and almost one-quarter of the population (72/301, 23.9%) moderate to severe symptoms (mean BDI-score of 23.9). Of the remaining respondents (63/301, 21%), 13% reported mild and 8% minimal symptoms. The overall mean baseline BDI score for the full sample was 29.84 (*SD* = 11.9). Most DC-users (67.4%) were receiving current treatment or some form of support or care from a mental health service and 69.8% reported current use of antidepressants.

Table 1. *Demographic and Clinical Characteristics of Survey Respondents at Baseline and of The Participants Having Completed at Least One Subsequent Assessment*

	Respondents				
	Total Group (N = 301)	**Baseline Only (*n* = 179)**	**Completers 2 or 3 assessments (*n* = 122)**	**Test statistic**	
Characteristic	***M* (*SD*) or frequency (%)**	***M* (*SD*) or frequency (%)**	***M* (*SD*) or frequency (%)**	**t(*df*) or $\chi^2(df)$**	***p***
Age in years (range 18-99), *M* (*SD*) [a]	50.2 (13.2)	48.22 (13.9) [a]	53.16 (11.4) [a]	*t*(297) = 3.25	.001
Female, *n* (%)	199 (66.1)	119	80	$\chi^2(1) = .03$	.87
Educational level, *n* (%)				$\chi^2(3) = 11.5$	.01
None, elementary school or vocational education	44 (14.6)	36 (12.7)	8 (2.7)		
Secondary education (middle or high school)	167 (55.5)	90 (29.9)	77 (25.6)		
Secondary vocational education and training	49 (16.3)	30 (10)	19 (6.3)		
Advanced vocational education and training and academic education	41 (13.6)	23 (7.6)	18 (6)		
Current depression (self-reported), *n* (%) [b]	216 (73.2) [b]	136 (63) [b]	80 (37) [b]	$\chi^2(1) = 3.7$	.06
Depressive symptoms (BDI-II), *M* (SD)	29.84 (11.9)	31.8 (11.4)	26.97 (12)	*t*(299) = -3.53	< .001
Severity of depressive symptoms (BDI-II) [c]				$\chi^2(3) = 11.9$	.008
Severe depressive symptoms (BDI-II), *n* (%)	166 (55.1)	112 (62.6)	54 (44.3)		
Moderate to severe depressive symptoms (BDI-II), *n* (%)	72 (23.9)	39 (21.8)	33 (27)		
Mild depressive symptoms (BDI-II), *n* (%)	39 (13)	19 (10.6)	20 (16.4)		
Minimal depressive symptoms (BDI-II), *n* (%)	24 (8)	9 (5)	15 (12.3)		
Current treatment, *n* (%) [d]	203 (67.4)	127 (62.6)	76 (37.4)	$\chi^2(1) = 2.5$	.12
Current antidepressant medication, *n* (%)	210 (69.8)	127 (60.5)	83 (39.5)	$\chi^2(1) = 2.9$	.59

Characteristic	Respondents				
	Total Group (N = 301)	**Baseline Only (n = 179)**	**Completers 2 or 3 assessments (n = 122)**	**Test statistic**	
	***M* (*SD*) or frequency (%)**	***M* (*SD*) or frequency (%)**	***M* (*SD*) or frequency (%)**	**t(*df*) or χ^2(*df*)**	***p***
Empowerment (NEL), *M* (*SD*)	2.06 (0.5)	1.99 (0.5)	2.15 (0.5)	*t*(299) = 2.78	.01
Self-Management (ASAD), *M* (*SD*)	78.11 (25.1)	75.15 (26.6)	82.45 (22)	*t*(299) = 2.50	.01
Functioning and Disability (WHODAS 2.0), *M* (*SD*)	35.7 (15.3)	38.11 (15.1)	32.17 (15)	*t*(299) = -3.36	.001

Note. Abbreviations: ASAD = Assessment of Self-management in Anxiety and Depression questionnaire; BDI, Beck Depression Inventory; M, Mean; NEL, Netherlands Empowerment List; SD, Standard deviation;; WHODAS, World Health Organization Disability Assessment Schedule.

[a] Due to 2 missing variables, n = 299 for the total group, n = 178 for baseline only, and n = 121 for completers.

[b] Due to 6 missing variables, n = 295 for the total group, n = 176 for baseline only, and n = 119 for completers.

[c] Based on the following BDI cut-off scores: 0-13 minimal depression; 14-19 mild depression; 20-28 moderate to severe depression; 29-63 severe depression.

[d] Includes any type of mental health care (e.g., general or specialized mental health care, and alternative support).

Completers, that is those respondents that had completed the baseline and at least one second assessment, were on average 4.95 years older ($t(297) = 3.25$, $p = .001$) and reported significantly higher levels of empowerment, self-management, less severe depressive symptoms and disability in major life domains compared to DC-users who had only completed the baseline assessment.

User engagement

Our cluster analysis of the forum use parameters as described in the Methods section resulted in four user engagement profiles: *very low* (profile 1), *low* (profile 2), *medium* (profile 3), and *high* (profile 4). The user parameters for the total study period (six months) are listed in Table 2. Baseline engagement profiles did not significantly differ for age, gender, current depression, current treatment or medication, nor for the baseline scores on empowerment, self-management, depressive symptoms, and disability. However, results did show significant differences between participants completing the baseline assessment only and participants that completed one or two assessments for the 'very low' engagement profile (177/301, 59%), of which 34% (60/177) participated in a second assessment and 66% (117/177) completed baseline only, $\chi2(3) = 27.14$, $p < .001$ (see Appendix).

Table 2. *DC User engagement for The Total Study Group and for the Engagement Profiles at six months*

Engagement parameter	**Total study group (N = 301)**	**Engagement Profile** ***Very Low* Engagement (profile 1) (*n* = 177)**	***Low* Engagement (profile 2) (*n* = 87)**	***Medium* Engagement (profile 3) (*n* = 30)**	***High* Engagement (profile 4) (*n* = 7)**	**Test Statistic**	
	***M* (*SD*)**	***M* (*SD*)**	***M* (*SD*)**	***M* (*SD*)**	***M* (*SD*)**	***F*(3,297)**	***p***
Total session duration in hours	5.48 (22.37)	0.37 (1.1)	2.35 (2.43)	18.84 (17.04)	116.01 (86.20)	177.51	< .001
Number of page views	322.19 (1117.14)	25.85 (41.71)	161.18 (103.12)	1315.33 (1015.74)	5560 (4159.86)	175.63	< .001
Number of posts	14.21 (58.45)	0.33 (1.33)	5.79 (5.81)	44.8 (47.46)	338.7 (158.63)	363.26	<. 001

Note. Abbreviations: DC = Depression Connect; *M* = Mean; *SD* = Standard deviation

Outcomes

Table 3 lists the results of the models investigating change in outcomes over time (days of DC-use). We computed a significant increase in empowerment (NEL) over time (in days), beta = 0.00078, SE = 0.00022, *p* = .001, with a small effect size, Cohen's *d* = 0.36, 95% CI [0.15, 0.57]. Self-management (ASAD) also increased over time, beta = 0.0222, SE = 0.011, *p* = .046, again with a small effect size, Cohen's *d* = 0.22, 95% CI [0.0, 0.43]. Depressive symptoms (BDI-II) significantly decreased over time with a small effect size, beta = -0.0244, SE = 0.00612, *p* < .01, Cohen's *d* = 0.44, 95% CI [0.21, 0.66]. Also, disability (WHODAS 2.0) significantly decreased over time with a small effect sizes, beta = -0.0212, SE = 0.00693, *p* = < .001, Cohen's *d* = 0.29, 95% CI [0.10, 0.47].

Figure 1 depicts the (changes in) outcomes and session duration for the participants who completed the baseline assessment only (panel 1, n = 179) and for those that completed at least two or all three assessments (panel 2, n = 122). The graphs present data modeled using a longitudinal mixed model regression analysis for session duration for each individual session (black dots), empowerment (NEL), self-management (ASAD), depressive symptoms (BDI-II), and functioning and disability (WHODAS 2.0) over time, including the baseline means for each outcome. They show an increase in empowerment and self-management, and a decrease in depressive symptoms and disability over time (days of engagement at the online peer support community DC).

Engagement profiles were not significantly associated with changes in any of the outcomes at three or six months, as is indicated by the nonsignificant effects for the dependent variable by engagement profile, empowerment, *F*(3, 176) = 0.07, *p* = .98; self-management, *F*(3, 169) = 0.1, *p* = .96; depressive symptoms, *F*(3, 184) = 0.14, *p* = .94; functioning and disability, *F*(3, 181) = 0.2, *p* = .9, and the nonsignificant time by profile interactions, empowerment, *F*(3, 131) = 0.55, *p* = .65; self-management, *F*(3, 126) = 0.92, *p* = .43; depressive symptoms *F*(3, 140) = 0.09, *p* = .96; and functioning and disability, *F*(3, 158) = 0.09, *p* = .96.

Table 3. *Linear Mixed Model Analysis for the Outcomes: Estimated Marginal Means and Effect Sizes*

	Baseline	**3-months (day 95)**	**6-months (day 186)**	**Fixed effect of time**			**Effect size day 0 to day 186** [f]		
	EMM (SE)	**EMM (SE)**	**EMM (SE)**	**Change per 100 days** [e]	**F(*df*)**	***p***	**Cohen's *d***	**95% CI**	
Outcomes								*LL*	*UL*
NEL, Empowerment [a]	2.17 (0.01)	2.24 (0.02)	2.32 (0.04)	.078	F(1, 136) = 12.5	.001	0.36	0.15	0.57
ASAD, Self-management [b]	83.44 (0.7)	85.56 (0.98)	87.58 (1.89)	2.22	F(1, 132) = 4.05	.046	0.22	0.0	0.43
BDI-II, Depressive symptoms [c]	26.71 (0.36)	24.4 (0.55)	22.18 (1.04)	-2.44	F(1, 147) = 15.9	< .001	0.44	0.21	0.66
WHODAS 2.0, 36 items, Disability [d]	31.69 (0.53)	29.68 (0.60)	27.76 (1.11)	-2.12	F(1, 164) = 9.33	.003	0.29	0.10	0.47

Note. We used a linear mixed model with time (day) and baseline value of the dependent variable as fixed factor, and subject within time (day) as random effect. Abbreviations: ASAD = Assessment of Self-management in Anxiety and Depression questionnaire; BDI = Beck Depression Inventory; EMM = Estimated Marginal Means; *LL* = lower limit; *UL* = upper limit; NEL = Netherlands Empowerment List; SE = Standard Error; WHODAS = World Health Organization Disability Assessment Schedule.

[a] NEL: Scores range from 0-4; with higher scores indicating greater empowerment.

[b] ASAD: Scores range from 0-180; with higher scores indicating a higher use of self-management strategies.

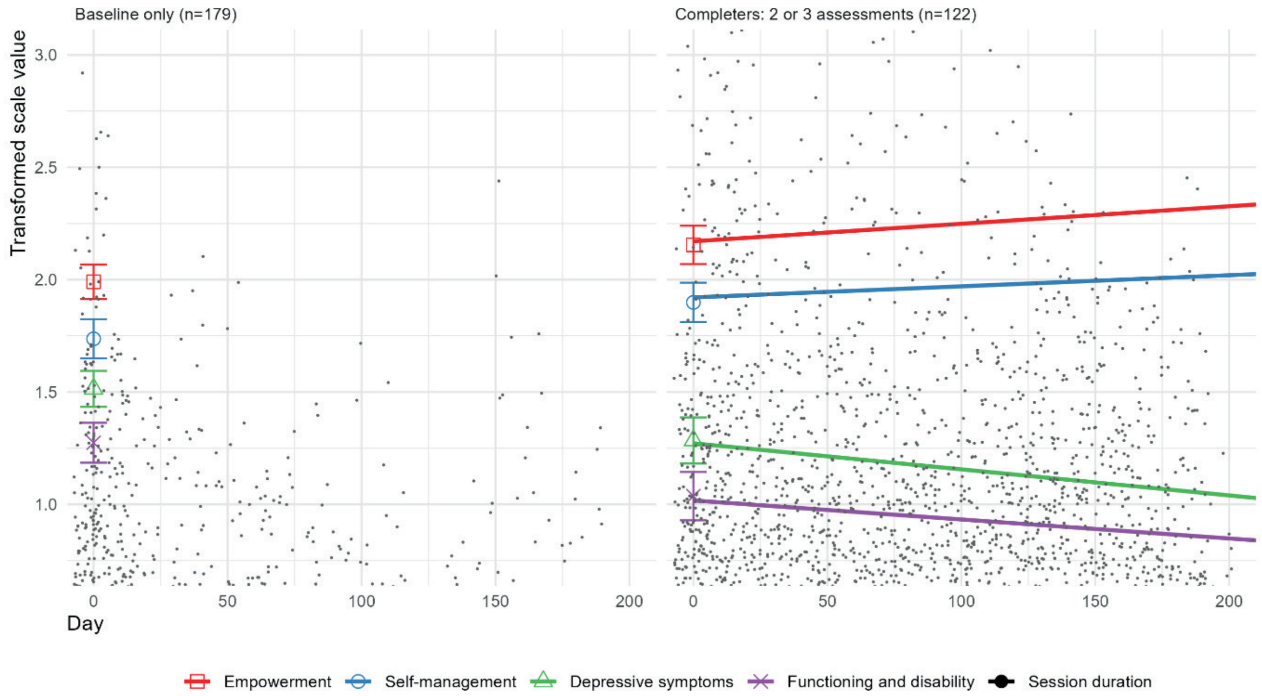
[c] BDI-II: Scores range from 0-63; with higher scores indicating more (severe) symptoms.

[d] WHODAS 2.0: Scores range from 0-144; with higher scores indicating more disability.

[e] Reflects the change in the outcome per 100 days, which is calculated by multiplying the beta value with 100.

[f] To calculate effect sizes, we used the model in which the baseline value of the outcome variable as a covariate was not included since in the model including this covariate the estimate of the intercept's standard deviation was naturally almost zero.

Figure 1. *Session Duration and Changes Over Time For Empowerment, Self-Management, Depressive Symptoms, and Functioning and Disability For Days of Depression Connect-Use*



Note. For the figure, scale values are transformed to a range from 0 to 4. To avoid overlap, the value of self-management is shifted 0.4 up and values for functioning and disability 0.25 down. Session duration is transformed to the square root of duration in minutes and divided by 5 so that most values are in the figure. Lines are based on values predicted by the model. Values at day 0 are actual means with the confidence level.

Discussion

Principal Findings

Although potential benefits of engaging in peer support for people with severe mental illness (SMI) are widely acknowledged (Fortuna et al., 2022; Griffiths et al., 2009a), peer support studies for online delivered intervention types targeting depression are limited (Crisp et al., 2014; Griffiths et al., 2012), and the processes for user engagement remain unclear (Carron-Arthur et al., 2015; Davis et al., 2022). In the current longitudinal user survey at the online peer support community Depression Connect, we explored patterns for user engagement and examined whether the user profiles were associated with recovery-oriented outcomes. To quantify baseline-to-six-month changes in empowerment, self-management, depressive symptoms, and functioning and disability in the users of DC, our online peer support community, and considering the complex interplay of relevant aspects of user engagement in PSIs, we entered the user data logs of three parameters (i.e., total session duration, page views, number of posts) into a cluster analysis, resulting in four engagement profiles. The majority of the survey respondents (177/301, 59%) were shown to have had *very low* or *low* engagement levels (87/301, 29%), with 10% having a *medium* (30/301) and 2% *high* user profiles (7/301). However, none of the profiles showed significant differences for age, gender, having a current depression, or receiving treatment at the time of assessment, nor with regard to the baseline scores for empowerment, self-management, depression, and functioning and disability. All recovery-oriented outcomes had improved over time, but, contrary to our hypothesis, the nature and intensity of DC-user engagement were not significantly associated with any of these improvements.

Findings in Context

The number of user surveys and RCTs for online depression PSIs are limited, but results are promising. Although our results did not show a significant relation between level of user engagement and recovery, Griffiths and colleagues (2012) reported positive results for engaging in an online depression PSI in their trial (Crisp et al., 2014; Griffiths et al., 2012). They found that depressive symptoms reduced at long-term (6 and 12 months) and empowerment may improve at short-term (post-intervention, at 3 months). Furthermore, reviews with and without meta-analyses for PSIs that include a heterogeneous population, primarily individuals with SMI, report positive changes for psychosocial outcomes (Fortuna et al., 2020; Fortuna et al., 2022; Lyons et al., 2021; White et al., 2020), more specifically for self-efficacy and hope (Bryan & Arkowitz, 2015; Burke et al., 2019; Chien et al., 2019; Fuhr et al., 2014; Huang et al., 2020; Lloyd-Evans et al., 2014). We confirmed this in our new and updated meta-analysis including PSIs for mental illness (Smit et al., 2022). However, research on peer support is associated with methodological issues (e.g., establishing model fidelity is not possible at this point; Fortuna et al., 2022). Therefore, results of this longitudinal user survey as well as results from the abovementioned PSI studies should be interpreted with caution.

Considering the level of user engagement, it is generally known that online communities are associated with low engagement rates (Carron-Arthur et al., 2014; Davis et al., 2022). This is often referred to the 1%-rule (Carron-Arthur et al., 2014; Van Mierlo, 2014), and is in line with our results. Yet, our study adds to the current literature since the results increase the insight in the intensity and nature of user engagement for online (depression) PSIs. Further research is needed to better understand the relation between levels of user engagement and positive changes for recovery.

Flexible User Engagement

In an attempt to create as true a proxy as possible for the way the participants to our study used the DC platform, we included multiple indicators that we thought would reflect the nature of their forum use best. Yet, our results surprisingly showed that the frequency and nature (passive versus active) of user engagement appears not to be associated with recovery. Where we focused on presence and participation rates on DC, the CAPE model states that a broad range of factors should be incorporated when operationalizing user engagement. These include metrics on the factors Connect (how many people are interested), Attend (e.g., presence, how many logins), Participate (e.g., active engagement), and Enact (making use of online learned skills in daily life) (Davis et al., 2022; Piotrowska et al., 2017). Adding to the current knowledge base on user engagement, our results suggests that it might be too simplistic to assume that there is an optimal or specific engagement pattern or style that is directly related to positive outcomes associated with the use of PSIs (Carron-Arthur et al., 2015). Since self-determination is a crucial aspect of the recovery-oriented approach, that is reflected in our PSI, voluntary use of the program seems important (Solomon, 2004). Arguably, the need for support from peers or the intention to support peers depends on the stage of depression or coping levels, which affects the intensity (i.e., frequency or duration) and nature of a person’s forum engagement (e.g., posting to ask for help or responding to help others; Lueck, 2018). In line with our qualitative evaluation of DC user experiences, the data presented here might indicate that user modes are indeed used interchangeably over time, developing and deploying different engagement styles (i.e., reading, posting, or responding) according to personal needs (Smit et al., 2021). These shifts in forum use then make it difficult to capture the effects of DC-use in such quantitative terms as engagement profiles. Far rather, by their design, online PSIs appear to provide users with an accessible digital realm where they are free to choose individual modes of engagement that match their current needs in their search for recovery.

Quantity versus quality of user engagement. Additionally, the perceived quality of forum posts might be a relevant factor to include when defining user engagement in terms of nature and intensity. Possibly, low engagement with the DC community suffices to benefit from peer support if a recently published post answers a specific question or explores a relevant topic effectively, satisfying the current need of individual users (Lee, Yang, & Rim, 2014). DC-users with queries about treatment options, for instance, may not have needed to spend much time on the platform to find pertinent information or to check whether they had received a fitting response. In turn, if a user is looking for (online) friendship (to create a sense of belonging), he or she is likely to spend more time on the forum and show more active engagement in order to connect with peers. Taken together, it may well be the personal needs and goals and the perceived quality of the forum content that ultimately determine whether and how users engage in and benefit from online peer support communities like DC.

Potential disadvantages of active user engagement. From a different perspective, two potential disadvantages of active forum engagement might have defeated the hypothesized positive association between high user engagement and the experienced benefits (recovery indices) of DC. First, the data showed that high-frequency users (high engagement) posted significantly more messages than the users with the other three profiles (very low, low, and medium engagement). This might imply that frequent users predominantly posted messages for (i.e., responded to) peers seeking support, focusing less on their own needs and recovery. According to the helper-therapy principle (Riessman, 1965), high-frequency users may experience positive feelings since they perceive helping peers as meaningful. In line with the central drawback that DC-users emphasized in our qualitative study, this active style may also have increased distress levels by their feeling responsible for their peers' well-being or by their identifying with the problems of fellow users too much (Shalaby & Agyapong, 2020). Second, as observed in clinical practice (Gmeinwieser, Kuhlencord, Ruhl, Hagmayer, & Probst, 2020) and our qualitative DC study (Smit et al., 2021), high engagement in supportive interactions may encourage self-reflection, uncovering problems users were not (as) aware of before, which might be both distressing and healing. Thus, in comparison to passive users, active engagers run a greater risk of being exposed to the disadvantages of peer support, possibly increasing their disease burden due to a heightened sense of responsibility for others and an increased awareness of their personal issues.

Assessing Recovery in Online Peer Support

Finally, other recovery-oriented outcomes may be more relevant for evaluating an unstructured online peer support community such as DC. Empowerment and self-management may be attributes that would characterize more advanced stages of recovery from mental illness such as depression better since they take time to develop and generally require guidance from a non-peer (i.e., a [para-]professional) (Chinman et al., 2014; Johansson et al., 2021), face-to-face PSI format (Burke et al., 2019; van Gestel-Timmermans, Brouwers, van Assen, & van Nieuwenhuizen, 2012; White et al., 2020), or a wider supportive context involving family or friends (Sibitz et al., 2011; Tjaden et al., 2021). Moreover, considering the informal nature and flexible, free use of our platform, and the fact that our sample mostly consisted of individuals with moderate to severe depressive symptoms, smaller goals such as an increased sense of being (emotionally) supported or finding new hope are probably more feasible (Borghouts et al., 2021).

Limitations

This study has several limitations. The first lies in the operationalization of user engagement. Although, rather than opting for (more frequently used) self-report measures, we tried to objectively quantify forum engagement by using logged user data (total time spent on the platform and the number of page views and posts), there are other potentially relevant indicators of engagement, such as the number of posts the user reads (van Uden-Kraan et al., 2008), the length of threads (Lee et al., 2014), and the number of replies received (Lee et al., 2014; Pan, Feng, & Shen, 2020). Particularly for individuals with depression, these activities and interactions reflecting recognition and support may reduce stress and negative emotions (Wright, 2000). Unfortunately, however, we were unable to extract these parameters from our user data logs. Second, the results of our previous qualitative exploration of DC-user experiences primarily related to users with an active engagement style. In this quantitative study, the number of high-frequent and actively engaged users – those posting significantly more than peers with other engagement profiles – was too small to detect any reliable effects on empowerment. Third, the lack of a comparison group in this longitudinal user survey precludes the exploration of causal relationships between DC-use and recovery. The effect sizes of RCTs comparing PSIs for mental illness to a control group that we pooled in our meta-analysis were significant, though, both for clinical and personal recovery indices.

Last, the generalizability of our findings is limited as we evaluated self-selected samples, where the decision to participate may contain some inherent positive bias towards engaging in (online) peer support. It is possible that users with a low engagement profile were not motivated to complete follow-up assessments in our evaluation study since they lacked commitment to DC or may not have experienced any benefits of engagement. However, our study has an explorative character, with a naturalistic sample that informed us on the general and heterogeneous population of individuals with depression that are engaging in peer support. Given the observational character of our study, the internal validity is limited. We do not know whether the improved outcomes are related to DC-use, and to what extent other types of support, or the many other variables that are part of the real-world setting (e.g., the level of offline social support, self-stigma, and societal participation) influence these results. Regardless, considering the free and informal nature of our online peer-to-peer support environment that allows users to tune their use of the forum to their personal needs, and the improvements observed, our survey expand the current literature by focusing on an online depression PSI. The results underscore that this type of peer support appear to be beneficial and promote recovery among individuals with self-reported depressive symptoms. These promising results are not only reflected in our survey. Also previously conducted user surveys in PSIs, underscore benefits of peer support for clinical (Houston et al., 2002) and personal recovery (Fullwood et al., 2019).

Future research

Since the various engagement profiles we identified indicate that DC-users appear to prefer a flexible use of the platform, insight into the content of their posts would foster the interpretation of our findings. We therefore recommend assessing the perceived quality of interactions (e.g., “Is the content helping you to cope with your depression?”) in future research on online PSIs. As alluded to above, quantitative variables such as thread length and the number of posts and responses or comments might tell us how effectively a topic was explored (Lee et al., 2014). Synthesizing qualitative data (e.g., content analysis) and quantitative data (e.g., metrics of use) of peer support user engagement would enhance our understanding of its implications for recovery. Also, in addition to clinical characteristics and (treatment) history of depression, it may be informative to describe the societal context of individual users. Possibly, the availability and quality of social support from family or friends may predict the users’ need for online peer support and explain low or high engagement. Since peer support is considered adjunctive to formal mental health care (Jacob, 2015), and it has been suggested that peer support encourages users to engage more actively in their professional treatment (Houston et al., 2002), it is worthwhile to investigate the usefulness and benefits of (online) peer support for concurrent professional therapy. Last, recovery is a multidimensional concept, but the various factors and processes involved are difficult to disentangle. Including comprehensive measurements in which the umbrella concepts of clinical, personal, and functional recovery-related indices are assessed separately and in-depth, such as is the case in the Recovery Assessment Scale (RAS), might improve the validity of findings.

Conclusions

This longitudinal user survey provides insight into the characteristics of user engagement in Depression Connect, an online peer support community for depression. Active engagement was limited to a small group of DC-users and was not significantly associated with superior improvements in empowerment and secondary recovery-oriented outcomes. Users appear to attune the intensity and nature of their forum use to their personal recovery pathway and current needs, where their engagement levels may shift from low to high, and from passive to active. Corresponding to the self-determination theory, the autonomy to choose the level of engagement might be one of the most valued and effective features of intervention types like DC, whereas in other more formal supportive environments for depression a certain level of engagement is predetermined. Future online PSI studies should explore the content and quality of user interactions to determine what constitutes optimal user engagement, where flexibility and usefulness match users’ clinical needs and their motives to seek and offer online peer support.

CHAPTER 5

The Effectiveness of Peer Support for Individuals With Mental illness: Systematic Review and Meta-Analysis

Smit, D., Miguel, C., Vrijsen, J. N., Groeneweg, B., Spijker, J., Cuijpers, P. (2022). The effectiveness of peer support for individuals with mental illness: systematic review and meta-analysis. *Psychological Medicine,* 1–10. doi: 10.1017/S0033291722002422

Abstract

Background: The benefits of peer support interventions (PSIs) for individuals with mental illness is not well known. The aim of this systematic review and meta-analysis was to assess the effectiveness of peer support interventions (PSIs) for individuals with mental illness for clinical, personal, and functional recovery outcomes.

Methods: Searches were conducted in PubMed, Embase, and PsycINFO (December 18, 2020). Included were randomised controlled trials (RCTs) comparing peer-delivered PSIs to control conditions. The quality of records was assessed using the Cochrane Collaboration Risk of Bias tool. Data were pooled for each outcome, using random-effects models.

Results: After screening 3,455 records, 30 RCTs were included in the systematic review and 28 were meta-analysed (4,152 individuals). Compared to control conditions, peer support was associated with small but significant post-test effect sizes for *clinical recovery*, $g = 0.19$, 95% CI [0.11, 0.27], $I^2 = 10\%$, 95% CI [0-44], and *personal recovery*, $g = 0.15$, 95% CI [0.04, 0.27], $I^2 = 43\%$, 95% CI [1, 67], but not for *functional recovery*, $g = 0.08$, 95% CI [-0.02, 0.18], $I^2 = 36\%$, 95% CI [0, 61]. Our findings should be considered with caution due to the modest quality of the included studies.

Conclusions: PSIs may be effective for clinical and personal recovery of mental illness. Effects are modest, though consistent, suggesting potential efficacy for PSI across a wide range of mental disorders and intervention types.

Introduction

In recent years mental health care services and social organizations increased their focus on implementing peer support initiatives to promote recovery and expand the availability of support for individuals coping with mental illness (Stratford et al., 2017). This growing interest in peer support is stimulated by the World Health Organization (WHO), as they consider it a feasible tool which adds a person-centred, recovery, and rights-based approach to biomedical practices in mental health services (WHO, 2021). Also, the COVID-19 pandemic increases the need for community-based interventions such as peer support (Suresh, Alam, & Karkossa, 2021), since mental health problems may have exacerbated and mental health services may be less accessible (Salari et al., 2020).

Peer support involves a mutual exchange of practical and emotional support, based on "shared understanding, respect, and mutual empowerment between people in similar situations" (Mead, Hilton, & Curtis, 2001) with critical ingredients such as shared responsibility (Mead, 2003; Mead & MacNeil, 2006), hope, self-determination over one's life, and the use of lived experience knowledge (Repper & Carter, 2011; Slade et al., 2014; Solomon, 2004). These aspects are embedded within the varying peer support programs implementing different structures, content, duration, and delivery formats, targeting different populations, and evaluating a wide range of outcomes (Chien, Clifton, Zhao, & Lui, 2019; Lloyd-Evans et al., 2014).

Previous meta-analyses examining the effects of peer support interventions (PSIs) were focused on specific target groups, such as patients with (perinatal) (Huang et al., 2020) depression (Bryan & Arkowitz, 2015; Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011) or serious mental illness (SMI) (Chien et al., 2019; Fuhr et al., 2014; Lloyd-Evans et al., 2014), or only analyse specific outcomes (e.g., cost-effectiveness; Chien et al., 2019; Huang et al., 2020) and empowerment (Burke, Pyle, Machin, Varese, & Morrison, 2019) or included either one-to-one (White et al., 2020) or group interventions (Lyons, Cooper, & Lloyd-Evans, 2021).

To the best of our knowledge, no previous meta-analysis has examined the effects of peer support across all patient groups and intervention types. We conducted a comprehensive systematic review and meta-analysis of randomized controlled trials (RCTs) comparing the effects of any peer support intervention with control conditions. We focused on three pre-specified main outcomes – clinical, personal, and functional recovery - and, when possible, we also examined specific outcomes within these main categories (e.g., depressive symptoms, empowerment, and quality of life).

Methods

Protocol registration

This study adheres to the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) reporting guideline (Moher, Liberati, Tetzlaff, Altman, & The, 2009), and focuses on the effect of peer support for individuals with mental health disorders, corresponding to the main part of our protocol (https://osf.io/58urb). This protocol also includes our search for RCTs on peer support for relatives and caregivers of individuals with mental illness, which will not be reported here.

Search Strategy

We searched PubMed, Embase, and PsycINFO up to December 18th 2020, without language restriction. We used index terms from database-specific thesauruses as well as free text words indicative of mental illness and peer support (search strings are available in Appendix A). References of included trials and previous systematic reviews were reviewed for eligibility.

Identification and selection of studies

Two authors (DS and CM) independently screened titles and abstracts to identify eligible papers for inclusion. To determine final inclusions, full texts of the selected papers were examined. We included studies: (a) that were RCTs; (b) comparing any PSI format; (c) for adults with a clinical or self-reported mental disorder diagnosis, or a score above a cut-off on a standardized mental disorder symptom measure; (d) with care-as-usual (CAU), waiting list (WL), or other active (e.g., clinician-led therapies) or inactive comparators (e.g., an attention control website) (Griffiths et al., 2012); and (e) outcomes focusing on at least one of 3 categories: *clinical* (i.e., symptomatic) recovery (Slade et al., 2014; van Eck, Burger, Vellinga, Schirmbeck, & de Haan, 2018); *personal* recovery (e.g., empowerment; Mueser et al., 2006; van Weeghel, van Zelst, Boertien, & Hasson-Ohayon, 2019); *functional* recovery (e.g., quality of life; Mueser et al., 2006). For a definition of the categories, see Appendix B. Peers are defined as individuals recovered or in recovery from a mental illness. We excluded trials when the intervention was partially or co-delivered by a non-peer (e.g., a lay health worker), targeting substance use, somatic disorder self-management, or including (ex-)employees with mental illness due to their job (e.g., veterans). Any disagreement was resolved with a third author (P.C.), and central issues were discussed in meetings with all authors.

Data extraction and Risk of Bias Assessment

A standardized form was used by two authors (DS and CM) to extract data regarding study context, participants' and intervention characteristics, including diagnoses, intervention format, control condition, and outcome data. When multiple measurements or control groups were available, we followed our developed decision tool (see Appendix C).

Study authors DS and CM independently assessed included trials using the Cochrane Collaboration Risk of Bias (RoB) tool 2.0 (Higgins et al., 2011), resolving any discrepancy with a third researcher (PC). Each of the following RoB-domains were rated as high risk, some concerns, or low risk: (a) the randomization process; (b) deviations from the intended interventions; (c) missing outcome data (up to 10% drop out was rated as low risk); (d) inappropriate measurement of the outcome; (e) selection of the reported result. An overall RoB score was calculated for each study, following our approach as presented in Appendix C.

Outcome measures

Outcomes included three pre-specified recovery categories: (1) *clinical recovery*, indicating the degree of psychiatric symptomatology (Slade et al., 2014), with measures including the Brief Symptom Inventory (BSI), and Brief Psychiatric Rating Scale (BPRS); (2) *personal recovery*, concerning the extents of perceived recovery, sense of purpose, and personal agency (Mueser et al., 2006; e.g., Recovery Assessment Schedule [RAS], Empowerment Scale [ES]); (3) *functional recovery*, referring to quality of life and the degree of vocational and social functioning (Robinson, Woerner, McMeniman, Mendelowitz, & Bilder, 2004; e.g., World Health Organisation Quality of Life [WHOQOL], EuroQoL 5D [EQ-5D]).

Also, we examined subcategories within the main categories of outcomes: *clinical* recovery (*depressive symptoms*), *personal* recovery (*empowerment, RAS, hope*), and *functional* recovery (*quality of life, social support*, and *loneliness*). These subcategories of specific outcomes were pooled when a minimum of five trials were available. In Appendix B, a comprehensive definition for each outcome category is provided, with details on data extraction per category described in Appendix C, and corresponding instruments in Appendix D.

Statistical analysis

We conducted separate meta-analyses comparing PSIs and control conditions for each main group of outcomes (clinical, functional, and personal recovery) as well as subcategories of outcomes within the main groups (e.g., hope, quality of life). Effects were estimated at post-test, and when possible, at long-term follow-ups (≥ six months after randomization).

We calculated between-group effect sizes (Hedges' g) by using means, standard deviations and N. When these were not reported, we used dichotomous outcomes or other statistics (e.g., p value, t value) for calculating effect sizes. Intention-to-treat data were used. Effect sizes were pooled with a random-effects model, using the Hartung-Knapp-Sidik-Jonkman method (IntHout, Ioannidis, & Borm, 2014). Heterogeneity was estimated with the I^2 statistic and its 95% confidence interval (CI). In addition, we included prediction intervals (PI), which represent 95% CI of the predictive distribution of effects in future comparable trials.

Categorical moderators of effects were explored in subgroup analyses by using a mixed-effects model. We conducted subgroup analyses when a minimum of three studies were available per subgroup.

We estimated publication bias through visual funnel plot inspection, Egger's test (Egger, Smith, Schneider, & Minder, 1997), and with Duval and Tweedie trim-and-fill procedure (Duval & Tweedie, 2000). We conducted sensitivity analyses by: (a) excluding outliers (defined as studies whose 95% CI effect size did not overlap with the 95% CI of the pooled effect), and (b) exploring the influence of RoB in the results. All meta-analyses were conducted in version 4.1.1 of R, using the packages *meta* (Balduzzi, Rücker, & Schwarzer, 2019), *metafor* (Viechtbauer, 2010), and *dmetar* (Harrer, Cuijpers, Furukawa, & Ebert, 2019).

Results

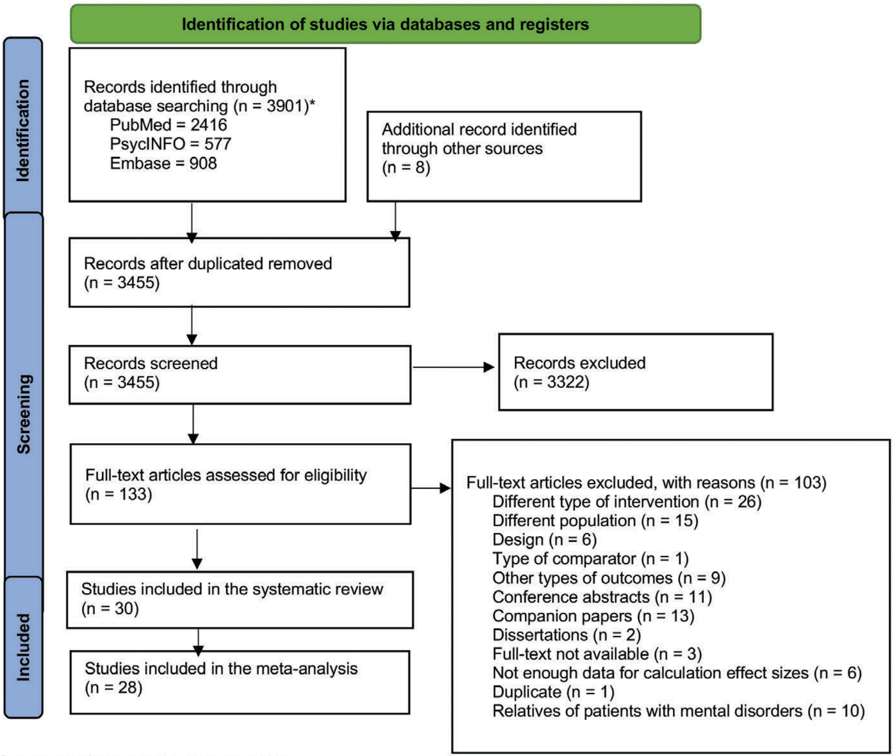
Inclusion of Studies

The PRISMA flowchart is presented in Figure 1. We screened 3,455 hits, and we examined the full-text of 133 studies. A total of 30 studies (for references, see Appendix E) were included, of which 28 trials and 4,152 participants, were included in the meta-analysis. Three studies (Field, Diego, Delgado, & Medina, 2013; Ludman et al., 2007; Mathews et al., 2018) included a clinician-led group as comparator (e.g., Interpersonal Psychotherapy [IPT] or Cognitive Behavioural Therapy [CBT]), including one overlapping trial (Ludman et al., 2007) which examined a control condition and a clinician-led comparator. Due to the limited number of studies, we did not pool trials with clinician-led comparators. A narrative description of these studies is presented in Appendix F.

Study Characteristics

Selected characteristics of 30 included studies are presented in Appendix D. Two main subgroups were identified across the included trials: patients with SMI (20 trials) and individuals with depression (7 trials). SMI studies included a heterogeneous group of patients including but not limited to psychosis, depressive disorders, anxiety disorders, or bipolar disorders. The majority of depression studies (5 trials) focused on perinatal depression (Dennis, 2003; Dennis et al., 2009; Gjerdingen, McGovern, Pratt, Johnson, & Crow, 2013; Letourneau et al., 2011; Shorey et al., 2019), with participants scoring above a cut-off on a questionnaire. One study focused on women with eating disorders (Ranzenhofer et al., 2020). Most studies had CAU (16 trials) or WL (9 trials) as a control condition.

Figure 1. *PRISMA Flow Diagram Describing the Selection and Inclusion Process*



* Searches performed at 18th December 2020

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

In 12 trials the PSI consisted of group meetings, 17 evaluated one-to-one peer support, and one trial implemented a mixed format. Face-to-face delivery was most common (16 trials), three trials evaluated telephone-based support, two trials examined internet support groups, and nine trials examined a mixed intervention, bringing together the latter formats. Intervention duration and frequency was heterogeneous and reported inconsistently, ranging from three weeks to six months with weekly meetings or a more flexible frequency.

Risk of Bias

Overall, there is a high RoB in the majority of included studies: 21 trials were rated at high risk (21/30, 70%), six studies were judged as having some concerns for risk of bias (6/30, 20%), and only three studies met criteria for low risk of bias (3/30, 10%). Focusing on the separate RoB domains, twelve studies (12/30, 40%) were rated at low risk of bias for domain 1, due to reporting an adequate randomization process. Due to the unstructured naturalistic approach of peer support, 23 studies (23/30, 77%) were rated at low risk in domain 2 (deviations from the intended interventions). Ten trials (10/30, 33%) were rated as low RoB in domain 3 due to missing outcome data. Thirteen trials (13/30, 43%) were judged at low risk in domain 4 due to measurement of the outcome, using self-report measures only. For domain 5, only five studies (5/30, 17%) were prospectively registered and were rated at low risk (see Figures G1 and G2 in Appendix G, and Appendix H for RoB rating per domain and study).

Clinical recovery

The pooled effect size at post-test across 22 PSI studies measuring *clinical recovery* was significant, with $g = 0.19$, 95% [CI 0.11, 0.27] (see Table 1 and Figure 2). Heterogeneity was low, $I^2 = 10\%$, 95% CI [0, 44]. The PI was consistent with benefit, overlapping completely with the 95% CI.

For the subgroup of patients with SMI (Boevink, Kroon, van Vugt, Delespaul, & van Os, 2016a; Cook et al., 2012a; Corrigan et al., 2017; Davidson et al., 2004; Johnson et al., 2018; Kaplan, Salzer, Solomon, Brusilovskiy, & Cousounis, 2011; Mahlke et al., 2017; O'Connell et al., 2018; Pfeiffer et al., 2019; Rivera, Sullivan, & Valenti, 2007; Rogers et al., 2016; Russinova et al., 2014; Solomon & Draine, 1995), the effect size was significant, $g = 0.18$, 95% CI [0.10, 0.26] (14 trials). However, for the subgroup of patients with depression (Dennis, 2003; Dennis et al., 2009; Gjerdingen et al., 2013; Griffiths et al., 2012; Letourneau et al., 2011; Ludman et al., 2007; Shorey et al., 2019), no significant effects were detected, $g = 0.19$, 95% CI [-0.20, 0.58] (7 trials]. In the same line, no significant effects were found when pooling 12 trials that specifically reported *depression* outcomes. Subgroup analyses to examine potential moderators of intervention effects showed no significant differences between subgroups (see Appendix I). There were significant differences in effects based on RoB levels, $p = 0.016$; $Q_2 = 8.30$, with the three studies rated at low risk showing a significant effect of $g = 0.52$, 95% CI [0.29, 0.76].

Table 1. *Effects for Clinical Recovery of Peer Support Interventions Compared with CAU, WL or Other Control Conditions: Hedges g* [a]

Clinical recovery	No. of trials	*g* [95% CI]	I^2 [95% CI]	*p*	PI
Main effect					
All studies pooled	22	0.19 [0.11, 0.27]	10 [0, 44]	< .001	0.11-0.27
Subgroup of patients					
Individuals clinically diagnosed with SMI	14	0.18 [0.10, 0.26]	0 [0, 55]	< .001	0.10-0.26
Individuals with depressive symptoms (k = 6 cut-off, k = 1 diagnosis) [b]	7	0.19 [-0.20, 0.58]	57 [0, 81]	.27	-0.67-1.05
Specific outcomes					
Depressive symptoms	12	0.14 [-0.02, 0.30]	41 [0, 70]	.09	-0.13-0.41
Publication bias					
Adjusting for publication bias [c]	23	0.18 [0.10, 0.27]	18 [0, 50]	< .001	0.10-0.27
Sensitivity analyses					
Outlier excluded	21	0.20 [0.14, 0.27]	0 [0, 47]	< .001	0.14-0.27
Risk of Bias [d]					
High Risk	15	0.15 [0.06, 0.25]	11 [0, 49]	.001	NA
Some concerns	4	0.20 [0.14, 0.27]	0 [0, 85]	< .001	NA
Low Risk	3	0.52 [0.29, 0.76]	0 [0, 90]	< .001	NA
Long-term					
6 to 9 months	13	0.17 [0.08, 0.26]	0 [0, 57]	.002	0.08-0.26
12 to 18 months [e]	8	0.10 [-0.21, 0.40]	63 [20, 83]	.48	-0.65-0.84

Note. Abbreviations: CAU = care-as-usual; CI = Confidence Interval; NA = Not Applicable; PI = Prediction Interval; WL = Waiting List.

[a] According to the random-effects model.

[b] k = 6 studies included individuals with depressive symptoms scoring above a cut-off on a standardized mental disorder symptom measure (of which k = 5 are on perinatal depression), and k = 1 study included adults with a clinical diagnosis.

[c] Egger's test was not significant ($p = .99$) and the number of imputed studies using Duvall and Tweedie trim-and-fill procedure was 23.

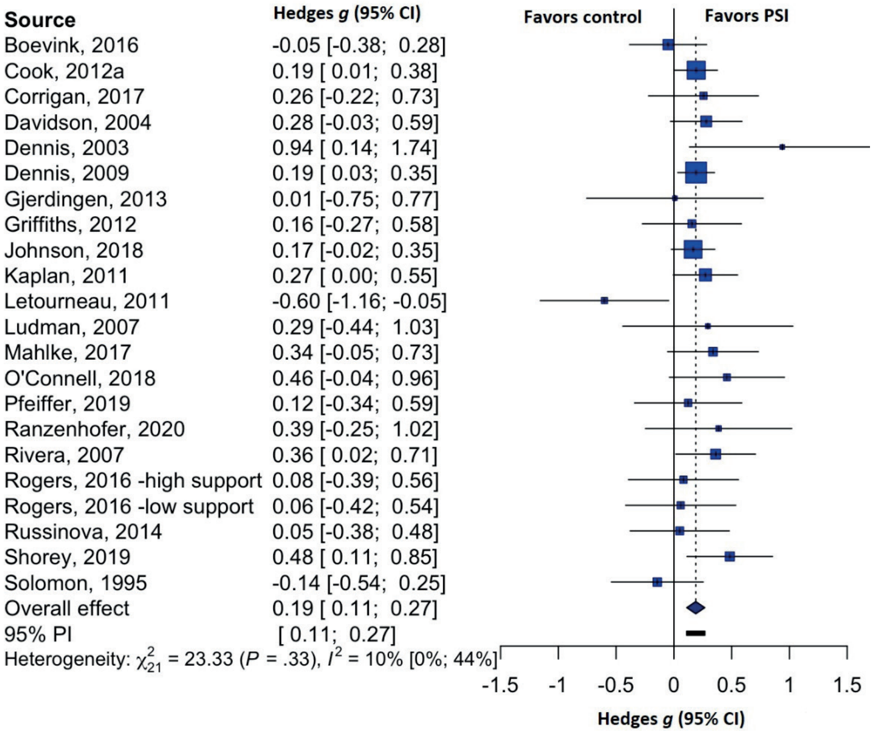
[d] The *p* value for the between-group effect sizes is significant ($p = .02$).

[e] Of the k = 8 studies only one study included 18 months follow-up data, the remaining studies reported 12 months follow-up data.

Inspection of funnel plots, Egger's test, p = 0.99, and the trim-and-fill procedure did not indicate significant publication bias (see Figure J1 in Appendix J). Removing one outlier (Letourneau et al., 2011) did not have a substantial impact on the effect, g = 0.20, 95% CI [0.14, 0.27].

Long-term effects for all clinical recovery outcomes indicated that the effect remained significant at six to nine months follow-up, g = 0.17, 95% CI [0.08, 0.26], but not at 12 to 18 months follow-up, g=0.10, 95% CI [-0.21, 0.40].

Figure 2. *Effect Sizes of Clinical Recovery Outcomes*



Source	**Hedges g (95% CI)**
Boevink, 2016	-0.05 [-0.38; 0.28]
Cook, 2012a	0.19 [0.01; 0.38]
Corrigan, 2017	0.26 [-0.22; 0.73]
Davidson, 2004	0.28 [-0.03; 0.59]
Dennis, 2003	0.94 [0.14; 1.74]
Dennis, 2009	0.19 [0.03; 0.35]
Gjerdingen, 2013	0.01 [-0.75; 0.77]
Griffiths, 2012	0.16 [-0.27; 0.58]
Johnson, 2018	0.17 [-0.02; 0.35]
Kaplan, 2011	0.27 [0.00; 0.55]
Letourneau, 2011	-0.60 [-1.16; -0.05]
Ludman, 2007	0.29 [-0.44; 1.03]
Mahlke, 2017	0.34 [-0.05; 0.73]
O'Connell, 2018	0.46 [-0.04; 0.96]
Pfeiffer, 2019	0.12 [-0.34; 0.59]
Ranzenhofer, 2020	0.39 [-0.25; 1.02]
Rivera, 2007	0.36 [0.02; 0.71]
Rogers, 2016 -high support	0.08 [-0.39; 0.56]
Rogers, 2016 -low support	0.06 [-0.42; 0.54]
Russinova, 2014	0.05 [-0.38; 0.48]
Shorey, 2019	0.48 [0.11; 0.85]
Solomon, 1995	-0.14 [-0.54; 0.25]
Overall effect	0.19 [0.11; 0.27]
95% PI	[0.11; 0.27]

Heterogeneity: χ^2_{21} = 23.33 (P = .33), I^2 = 10% [0%; 44%]

Note. Abbreviations: CI = Confidence Interval; PSI = Peer Support Intervention. Shown are standardized post-test effect sizes (Hedges g) of comparisons between PSIs and control conditions for clinical recovery relevant outcomes (overall [transdiagnostic] clinical symptoms or depression symptoms).

Personal recovery

The pooled effect size at post-test across 19 PSI studies measuring *personal recovery* was significant, g = 0.15, 95% CI [0.04, 0.27] (see Table 2 and Figure 3). Heterogeneity was moderate, I^2 = 43%, 95% CI [1, 67], although the PI [-0.16, 0.47] was wide and contained the null effect.

For the subgroup of individuals with SMI (Boevink et al., 2016b; Castelein et al., 2008; Cook et al., 2012a; Cook, et al., 2012b; Corrigan et al., 2017; Corrigan et al., 2018; Davidson et al., 2004; Johnson et al., 2018; Kaplan et al., 2011; Mahlke et al., 2017; Pfeiffer et al., 2019; Rogers et al., 2016; Rüsch et al., 2014; Russinova et al., 2014; Salzer et al., 2016; van Gestel-Timmermans, Brouwers, van Assen, & van Nieuwenhuizen, 2012), the effect size was significant, g = 0.15, 95% CI [0.02, 0.28] (17 trials). For individuals with depressive symptoms, the number of trials (Dennis, 2003; Griffiths et al., 2012) was too small to reliably detect effects. Pooling specific outcomes within personal recovery resulted in significant effects for *hope* outcomes, g = 0.13, 95% CI [0.03, 0.22], but not for *empowerment* or the *Recovery Assessment Scale*. In subgroup analyses we found no differences in effect of PSIs among potential moderators (see Appendix I).

No indications of publication bias were observed, Egger's test, p = 0.66, see Figure J2 in Appendix J. The effect size did not substantially change when excluding one outlier (Salzer et al., 2016), g = 0.13, 95% CI [0.05, 0.21]. Subgroup analyses did not detect differences in effects between RoB levels, although only one trial was rated at low risk and the impact of RoB is uncertain due to lack of power.

Long-term effects for all personal recovery outcomes showed nonsignificant results for both periods, six to nine months: g = 0.10, 95% CI [-0.10, 0.30], and 12 to 18 months follow-up: g = 0.54, 95% CI [-0.33, 1.41].

Table 2. *Effects for Personal Recovery of Peer Support Interventions compared with CAU, WL or Other Control Conditions: Hedges g* [a]

Personal recovery	**No. of trials**	***g* [95% CI]**	***I*^{2} [95% CI]**	***p***	**PI**
Main effect					
All studies pooled	19	0.15 [0.04, 0.27]	43 [1, 67]	.01	-0.16-0.47
Subgroup of patients					
Individuals clinically diagnosed with SMI	17	0.15 [0.02, 0.28]	48 [9, 71]	.02	-0.21-0.51
Individuals with depressive symptoms (both cut-off) [b]	2	0.18 [-1.11, 1.46]	NA	.33	NA
Specific outcomes					
Empowerment	13	0.25 [-0.10, 0.60]	84 [74, 90]	.15	-0.97-1.47
Recovery (RAS)	8	0.21 [-0.05, 0.47]	58 [9, 81]	.09	-0.39-0.81
Hope	5	0.13 [0.03, 0.22]	0 [0, 79]	.02	0.02-0.23
Publication bias					
Adjusting for publication bias [c]	24	0.23 [0.12, 0.35]	56 [31, 72]	< .001	-0.21-0.68
Sensitivity analyses					
Outlier excluded	18	0.13 [0.05, 0.21]	1 [0, 50]	.003	-0.01-0.27
Risk of Bias [d]					
High Risk	14	0.15 [0.01, 0.29]	56 [21, 76]	.003	NA
Some concerns	4	0.14 [0.03, 0.24]	0 [0, 85]	.01	NA
Low Risk	1	0.35 [-0.26, 0.95]	NA [NA]	.26	NA
Long-term					
6 to 9 months	12	0.10 [-0.10, 0.30]	64 [32, 81]	.28	-0.48-0.68
12 to 18 months [e]	7	0.54 [-0.33, 1.41]	93 [89, 96]	.18	-1.96-3.04

Note. Abbreviations: CAU = care-as-usual; CI = Confidence Interval; NA = Not Applicable; PI = Prediction Interval; WL = Waiting List.

[a] According to the random-effects model.

[b] Both studies (k = 2) included individuals with perinatal depressive symptoms scoring above a cut-off on a standardized mental disorder symptom measure.

[c] Egger's test was not significant (p = .66) and the number of imputed studies using Duvall and Tweedie trim-and-fill procedure was 24.

[d] The p value for the between-group effect sizes is not significant (p = .79).

[e] Of the k = 7 studies, only one study included 18 months follow-up data, the remaining studies reported 12 months follow-up data.

Functional recovery

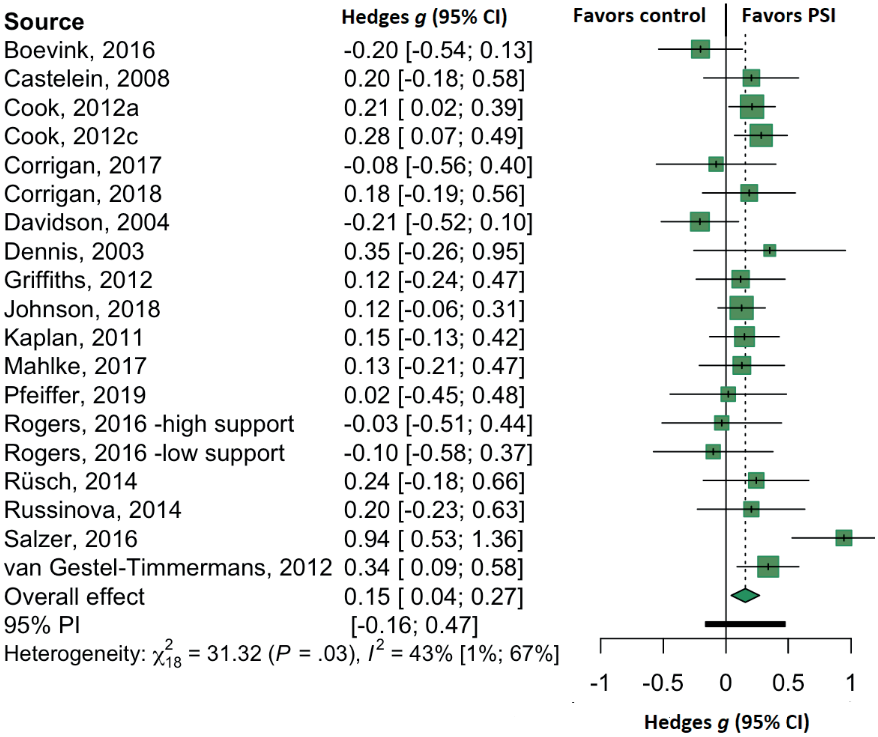
The pooled effect size at post-test across 25 PSI studies measuring *functional recovery* was nonsignificant, $g = 0.08$, 95% CI [-0.02, 0.18], with low heterogeneity, $I^2 = 36\%$, 95% CI [0, 61] (see Table 3 and Figure 4). The PI was wide and contained the null effect [-0.16, 0.32].

For the subgroup of patients with SMI (Boevink et al., 2016a; Cook et al., 2012a; Corrigan et al., 2017; Davidson et al., 2004; Johnson et al., 2018; Kaplan et al., 2011; Mahlke et al., 2017; O'Connell et al., 2018; Pfeiffer et al., 2019; Rivera et al., 2007; Rogers et al., 2016; Russinova et al., 2014; Solomon & Draine, 1995), the effect size was significant, $g = 0.18$, 95% CI [0.10, 0.26] (14 trials), but not for the six trials targeting individuals with depressive symptoms (Dennis, 2003; Dennis et al., 2009; Gjerdingen et al., 2013; Griffiths et al., 2012; Letourneau et al., 2011; Shorey et al., 2019), $g = 0.02$, 95% CI [-0.34, 0.37]. No significant effect sizes were observed in any of the examined specific outcomes: for *quality of life*, $g = 0.08$, 95% CI [-0.04, 0.19], *social functioning*, $g = 0.07$, 95% CI [-0.05, 0.18], and *loneliness*, $g = 0.09$, 95% CI [-0.05, 0.23]. Conducting subgroup analyses, we found no differences in effect of PSIs among potential moderators (see Appendix I).

No indications of publication bias were observed, Egger's test, $p = 0.74$, see Figure J3 in Appendix J. When one outlier was removed (Salzer et al., 2016), the effect size remained significant, $g = 0.06$, 95% CI [-0.01, 0.13]. Subgroup analyses showed no differences in effects between RoB levels. Pooling the three trials rated at low risk resulted in a nonsignificant effect of $g = 0.19$, 95% CI [-0.37, 0.76].

Long-term effects for all functional recovery outcomes demonstrated a significant effect size at six to nine months follow-up, $g = 0.14$, 95% CI [0.01, 0.27] (17 trials). At 12 to 18 months follow-up, effects were nonsignificant, $g = 0.38$, 95% CI [-0.21, 0.98].

Figure 3. *Effect Sizes of Personal Recovery Outcomes*



Source	Hedges *g* (95% CI)
Boevink, 2016	-0.20 [-0.54; 0.13]
Castelein, 2008	0.20 [-0.18; 0.58]
Cook, 2012a	0.21 [0.02; 0.39]
Cook, 2012c	0.28 [0.07; 0.49]
Corrigan, 2017	-0.08 [-0.56; 0.40]
Corrigan, 2018	0.18 [-0.19; 0.56]
Davidson, 2004	-0.21 [-0.52; 0.10]
Dennis, 2003	0.35 [-0.26; 0.95]
Griffiths, 2012	0.12 [-0.24; 0.47]
Johnson, 2018	0.12 [-0.06; 0.31]
Kaplan, 2011	0.15 [-0.13; 0.42]
Mahlke, 2017	0.13 [-0.21; 0.47]
Pfeiffer, 2019	0.02 [-0.45; 0.48]
Rogers, 2016 -high support	-0.03 [-0.51; 0.44]
Rogers, 2016 -low support	-0.10 [-0.58; 0.37]
Rüsch, 2014	0.24 [-0.18; 0.66]
Russinova, 2014	0.20 [-0.23; 0.63]
Salzer, 2016	0.94 [0.53; 1.36]
van Gestel-Timmermans, 2012	0.34 [0.09; 0.58]
Overall effect	0.15 [0.04; 0.27]
95% PI	[-0.16; 0.47]

Heterogeneity: $\chi^2_{18} = 31.32$ ($P = .03$), $I^2 = 43\%$ [1%; 67%]

Note. Abbreviations: CI = Confidence Interval, PSI = Peer Support Intervention
Shown are standardized posttest effect sizes of comparisons between PSIs and control conditions for personal recovery relevant outcomes (Empowerment, Hope or overall personal recovery assessed by the Recovery Assessment Schedule [RAS]).

Table 3. *Effects for Functional Recovery of Peer Support Interventions Compared With CAU, WL or Other Control Conditions: Hedges g* [a]

Functional recovery	No. of trials	*g* [95% CI]	I^2 [95% CI]	*p*	PI
Main effect					
All studies pooled	25	0.08 [-0.02, 0.18]	36 [0, 61]	.11	-0.16-0.32
Subgroup of patients					
Individuals clinically diagnosed with SMI	14	0.18 [0.10, 0.26]	0 [0, 55]	< .001	0.10-0.26
Individuals with depressive symptoms (k = 6 cut-off, k = 1 diagnosis) [b]	6	0.02 [-0.34, 0.37]	47 [0, 79]	.90	-0.66-0.70
Specific outcomes					
Quality of Life	18	0.08 [-0.04, 0.19]	32 [0, 61]	.18	-0.15-0.30
Social support	15	0.07 [-0.05, 0.18]	13 [0, 51]	.25	-0.07-0.20
Loneliness	7	0.09 [-0.05, 0.23]	25 [0, 67]	.17	-0.06-0.24
Publication bias					
Adjusting for publication bias [c]	26	0.09 [-0.01, 0.19]	39 [3, 62]	.08	0.18-0.37
Sensitivity analyses					
Outlier excluded	24	0.06 [-0.01, 0.13]	7 [0, 40]	.09	-0.01-0.13
Risk of Bias [d]					
High Risk	17	0.04 [-0.09, 0.17]	47 [7, 70]	.52	NA
Some concerns	5	0.13 [0.08, 0.18]	0 [0, 79]	< .001	NA
Low Risk	3	0.19 [-0.37, 0.76]	64 [0, 90]	.50	NA
Long-term					
6 to 9 months	17	0.14 [0.01, 0.27]	39 [0, 66]	.03	-0.18-0.46
12 to 18 months [e]	10	0.38 [-0.21, 0.98]	91 [85, 94]	.18	-1.54-2.30

Note. Abbreviations: CAU = care-as-usual; CI = Confidence Interval, NA = Not Applicable, PI = Prediction Interval, WL = Waiting List.

[a] According to the random-effects model.

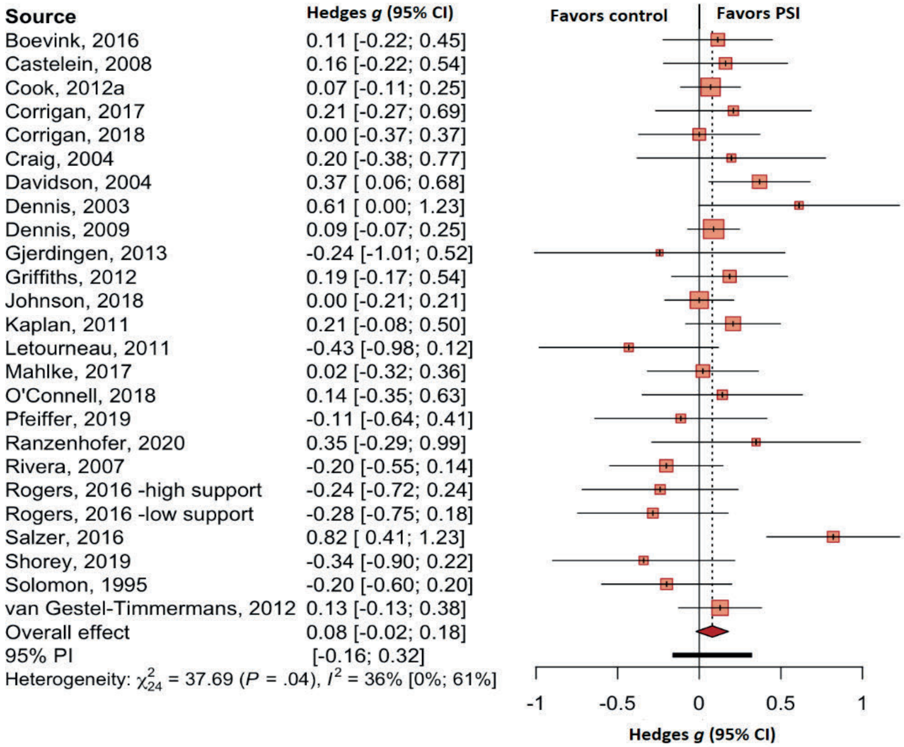
[b] k = 6 studies included individuals with depressive symptoms scoring above a cut-off on a standardized mental disorder symptom measure (of which k = 5 are on perinatal depression), and k = 1 study included adults with a clinical diagnosis.

[c] Egger's test was not significant ($p = .74$) and the number of imputed studies using Duvall and Tweedie trim-and-fill procedure was 26.

[d] The *p* value for the between-group effect sizes is not significant ($p = .45$).

[e] Of the k = 10 studies, only one study included 18 months follow-up data, the remaining studies reported 12 months follow-up data.

Figure 4. *Effect Sizes of Functional Recovery Outcomes*



Source	Hedges *g* (95% CI)
Boevink, 2016	0.11 [-0.22; 0.45]
Castelein, 2008	0.16 [-0.22; 0.54]
Cook, 2012a	0.07 [-0.11; 0.25]
Corrigan, 2017	0.21 [-0.27; 0.69]
Corrigan, 2018	0.00 [-0.37; 0.37]
Craig, 2004	0.20 [-0.38; 0.77]
Davidson, 2004	0.37 [0.06; 0.68]
Dennis, 2003	0.61 [0.00; 1.23]
Dennis, 2009	0.09 [-0.07; 0.25]
Gjerdingen, 2013	-0.24 [-1.01; 0.52]
Griffiths, 2012	0.19 [-0.17; 0.54]
Johnson, 2018	0.00 [-0.21; 0.21]
Kaplan, 2011	0.21 [-0.08; 0.50]
Letourneau, 2011	-0.43 [-0.98; 0.12]
Mahlke, 2017	0.02 [-0.32; 0.36]
O'Connell, 2018	0.14 [-0.35; 0.63]
Pfeiffer, 2019	-0.11 [-0.64; 0.41]
Ranzenhofer, 2020	0.35 [-0.29; 0.99]
Rivera, 2007	-0.20 [-0.55; 0.14]
Rogers, 2016 -high support	-0.24 [-0.72; 0.24]
Rogers, 2016 -low support	-0.28 [-0.75; 0.18]
Salzer, 2016	0.82 [0.41; 1.23]
Shorey, 2019	-0.34 [-0.90; 0.22]
Solomon, 1995	-0.20 [-0.60; 0.20]
van Gestel-Timmermans, 2012	0.13 [-0.13; 0.38]
Overall effect	0.08 [-0.02; 0.18]
95% PI	[-0.16; 0.32]

Heterogeneity: $\chi^2_{24} = 37.69$ ($P = .04$), $I^2 = 36\%$ [0%; 61%]

Note. Abbreviations: CI = Confidence Interval; PSI = Peer Support Intervention
Shown are standardized posttest effect sizes of comparisons between PSIs and control conditions for functional recovery relevant outcomes (i.e., Quality of Life or Social Functioning).

Discussion

In this comprehensive meta-analysis of 28 RCTs ($n = 4{,}152$), PSIs for patients covering a broad spectrum of mental illnesses was associated with superior outcomes compared with control conditions regarding: (a) *clinical* recovery at post-test, and six to nine months follow-up; (b) *personal* recovery at post-test; and (c) *functional* recovery limited to six to nine months follow-up. When examining specific groups, we saw that specifically in the SMI patients -individuals with serious mental disorders- peer support was associated with significant superiority to control conditions at post-intervention across all three recovery categories. For the subgroup of individuals with elevated depressive symptoms -most of them being perinatal women- no significant effects were found in any of the recovery categories. Nonetheless, the number of trials targeting this group was small and nonsignificant results could be due to a lack of power. Also, the analyses for more category-specific outcomes within each main outcome category were exploratory due to the small number of studies. Only the effect size for *hope*, considered part of personal recovery, was significant.

We found no significant differences in effect of PSIs among potential moderators (e.g., intervention delivery) for any of the outcomes, which could suggest that common values of peer support exceed disorder-specific needs and the intervention type. However, subgroup analyses should be considered with caution, since the number of trials for some categories was small and these analyses are likely underpowered. Accordingly, we could not analyze differences in effects between internet-based PSIs (2 trials) and traditional face-to-face interventions (16 trials; see Appendix I). Since the evidence-base for eHealth is increasing (Chan et al., 2022; Deady et al., 2017; Massoudi et al., 2019) and digital PSIs for individuals with SMI seem to be associated with positive changes for both clinical and psychosocial outcomes (Fortuna et al., 2020), the effectiveness for technology-based PSIs should be further investigated.

The pooled effect sizes, that were confirmed in sensitivity analyses, were small ranging from $g = 0.15$ for overall personal recovery to $g = 0.19$ for overall clinical recovery at post-test. A surprising finding was low to moderate heterogeneity, suggesting that the effects were consistent across wide varying studies. However, due to the relatively large width of the 95% CIs, caution must be applied. Moreover, although the effect size for clinical recovery appeared to be more robust, the prediction intervals for personal and functional recovery suggested that the effects are considerably uncertain. In addition, risk of bias was high for the majority of included studies and we could not reliably estimate its impact on the results of the meta-analysis.

Operating with a broad scope, including the largest number of trials on peer support to date, we found a significant though small effect size for *clinical* recovery. This was not detected in previous meta-analyses (Burke et al., 2019; Chien et al., 2019; Fuhr et al., 2014; Huang et al., 2020; Lloyd-Evans et al., 2014; Lyons et al., 2021; White et al., 2020), possibly due to a lack power. Considering the efficacy of peer support for *personal* recovery, we confirmed and extended the results of previous meta-analyses (Bryan & Arkowitz, 2015; Burke et al., 2019; Fuhr et al., 2014; Lloyd-Evans et al., 2014; Lyons et al., 2021; White et al., 2020). So far, outcomes for *functional* recovery are scarcely addressed in peer support meta-analyses (Fuhr et al., 2014; Lyons et al., 2021). Whilst only valid for the subgroup SMI and long-term analysis, we found significant effect sizes for functional recovery, with *quality of life* as most important outcome parameter. Overall, results indicate that peer support is of clinical relevance for individuals with mental illness, and not limited to reinforcing personal recovery following the generally accepted recovery-oriented approach (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; van Weeghel et al., 2019).

Limitations

The results of this study should be considered with caution because of several important limitations. First, measures for clinical, personal, and functional recovery differed considerably across studies. Second, long-term effects were limited to smaller samples of trials up to 12 months follow-up. Third, a major limitation of this study is the high risk of bias for the majority of trials, with limited reporting for many of the risk of bias items. Since peer support has an informal nature, it is difficult to quantitatively analyze these interventions. An established protocol would help to quantify variables that could be evaluated in trials, but this would restrict the open nature of PSIs. Still, since peer support has been increasingly considered an essential element for recovery there has been attempts to structure and professionalize PSIs (Chinman et al., 2016; SAMHSA, 2015). However, doubts remain because the core of peer support is its naturalistic approach (Fortuna et al., 2022). The feasibility, acceptability, and benefits of structuring and professionalizing PSIs needs further investigation. To improve the quality of studies, future research should implement clinician-rated instruments and prospective registration in clinical trial registries. Finally, though comparing the efficacy of PSIs with clinical psychotherapies seems relevant for implementing or referring to PSIs in mental health care, the number of trials was too small to conduct a meta-analysis for RCTs with a clinician-led comparator.

Conclusions

Engaging in a peer support intervention may be effective for reducing clinical mental illness symptoms, improving overall personal recovery, and more specifically hope. In particular for individuals with SMI, peer support demonstrated probable efficacy across the three recovery categories. Although effects were small, peer support is a potentially cost-effective and relatively easy to implement intervention, and may complement professional treatment. Therapists, general practitioners, and employees of recovery-oriented services may refer their clients to peer support initiatives to expand the individuals’ context to work on recovery when coping with mental illness.

CHAPTER 6

Summary and General Discussion

The studies in this thesis covered two main elements for the recovery-oriented approach in depression: (a) *experiential knowledge* (chapter 2), and (b) the benefits of engaging in *online peer support* (chapter 3 and 4), concluding with the effectiveness of peer support across a wide range of intervention types and mental illness (chapter 5). This final chapter starts with a summary of the chapters with the main findings clustered around the research questions. Subsequently, the main findings for *experiential knowledge* and *peer support* are discussed in relation to the existing literature, and reflected upon to integrate the qualitative and quantitative results. Additionally, strengths and limitations are identified, and suggestions for future research and clinical implications are described.

Summary

Chapter 1: *General Introduction*

In the first introductory chapter, the context and aims of this thesis are explained. Depression is a highly prevalent mental health condition worldwide. With persistent and recurring symptoms such as sadness, fatigue, and concentration problems, individuals with depression have to learn how to cope with depression in their daily lives. The recovery-oriented approach, which is widely acknowledged in mental health care, emphasizes that recovery is not limited to symptom reduction (i.e., clinical recovery). Recovery should be seen as an ongoing journey including multiple life domains such as physical, mental, and social needs of the individual. In the literature, clinical-, personal- and functional recovery could be distinguished. The latter two categories refer to processes for coping, and learning how to live with mental illness: living a meaningful life according to one's own values, and the degree of social functioning. Sharing one's own lived experiences on how to cope with mental illness, referred to as *experiential knowledge*, seems to support the recovery-oriented approach and is considered the bedrock of peer support. To facilitate the sharing of experiential knowledge, we co-created a new online peer support community for depression: "Depression Connect" (DC). DC is a digital platform that offers individuals to (anonymously) read or exchange experiences for coping with depression. The online community is hosted by the patient association for depression, the Dutch Depression Association.

In this thesis, we explored the patient's perspective on how to learn to cope with depression (interview study on the development of experiential knowledge, chapter 2), and examined both qualitatively (interview study, chapter 3) and quantitatively (longitudinal user survey, chapter 4) the usefulness of engaging in the online peer support community DC. To seek for empirical evidence for peer support for wide-ranging mental health problems, we used meta-analytic methods and pooled data of randomized controlled trials (RCTs) comparing peer support to a control condition (meta-analysis, chapter 5).

Chapter 2: *What do individuals with depression learn when coping with depression? What is needed to deploy self-management strategies for depression?*

In the qualitative interview study presented in **chapter 2**, the evolvement of experiential knowledge in depression was explored, by identifying the main themes that individuals with depression dealt with during coping with the illness, and to better understand the conditions for deploying self-management strategies. Opting for a broad perspective, we suggested a conceptual framework illustrating three continuously interacting *intra*personal levels: introspection, empowerment, and self-management, with the context of the individual at an interpersonal level for the development of experiential knowledge. Results indicate that a positive interaction between introspection, empowerment, and the environment might help patients to develop and sustainably use self-management strategies to manage the depression on the long-term. This in-depth description of patients' experiences encourages a holistic perspective on the dynamics of coping with depression.

Chapter 3: *What are the perceived benefits of engaging in the online peer support community Depression Connect? Are user experiences related to participation styles?*

Building on the findings for experiential knowledge presented in chapter 2, and primarily based on the need of potential users, we developed the online peer support community "Depression Connect" (DC). In **chapter 3**, we evaluated potential benefits of engaging in peer support. Based on interviews with a selection of DC-users, we found that participation in the online peer support community was associated with an increased sense of belonging, emotional growth, a sense of self-efficacy, and empowerment. Three modes of user engagement were identified that individually and together, related differentially to the users' appreciation of the platform: starting with reading only, evolving into posting and culminating in responding. As a truly interactive engagement style, responding played a key role in empowering users; being valuable to others boosted their belief in their own abilities. Primarily, the interviewees used the forum to explore and try (new) coping and social skills for later use in "real life". Our results suggest that due to the cyclical nature of depression participation styles tend to evolve and fluctuate. According to most interviewees, the autonomy in choosing how they engaged in DC was a core advantage of online peer support, distinguishing it from other forms of offline peer support or formal care.

Chapter 4: *What is the intensity and nature of user engagement in the online peer support community Depression Connect, and is this related to changes in recovery-related outcomes?*

In **chapter 4**, potential benefits for recovery by engaging in peer support are further assessed with a longitudinally user survey among 301 users of the online peer support community DC. To quantify baseline-to-six-month changes in empowerment, self-management, depressive symptoms, and functioning and disability in the users of DC, we entered the user data logs of three parameters (i.e., total session duration, page views, number of posts) into a cluster analysis, resulting in four engagement profiles. Active engagement was limited to a small group of DC-users. The intensity of engagement was not significantly associated with improvements in recovery-oriented outcomes. This suggests that it might be too simplistic to assume that there is an optimal or specific engagement pattern or style that is directly related to positive outcomes associated with the use of peer support. Users appear to attune the intensity of their forum use to their personal recovery pathway and current needs.

Chapter 5: *Are peer support interventions for individuals with mental illness effective for clinical, personal, and functional recovery?*

In **chapter 5**, we adopted a broad perspective, and examined the effectiveness of peer support interventions across a wide range of mental illness in a systematic review and meta-analysis. We included outcomes for clinical, personal, and functional recovery, and any type of peer support compared to control conditions. In the meta-analysis 28 RCTs (n = 4,152) were included. Peer support was associated with superior outcomes compared with control conditions for: (a) clinical recovery at post-test, and 6 to 9 months follow-up; (b) personal recovery at post-test; and (c) functional recovery limited to 6 to 9 months follow-up. In particular for individuals with serious mental illness (SMI), peer support demonstrated probable efficacy across the three recovery categories. Effects were small though consistent, ranging from Hedges g = 0.15 for personal recovery to g = 0.19 for overall clinical recovery at post-test. Results suggest that peer support may be beneficial and complement professional treatment.

General discussion

The Development of Experiential Knowledge in Depression

The results of the qualitative interview study in chapter 2 suggest that although experiential knowledge for depression is unique for each individual, universal themes at an intrapersonal level could be recognized: introspection, self-management, and empowerment. It is important to realize that these findings concentrate on individuals with persistent or recurrent depression. In particular, self-management and empowerment are acknowledged in former studies on recovery for depression.

As one of the few studies on recovery for depression addressing self-management, van Grieken and colleagues (2014) showed that there are wide-ranging strategies for coping with depression that patient's perceive helpful. Most importantly, this qualitative concept map study suggests that actively dealing with the illness and engaging in social or work activities is relevant when coping with longer-term depression. This mirrors our results on experiential knowledge, were actively managing depressive symptoms with the use of self-help strategies (e.g., practicing meditation), engaging in activities, and having contact with others were reflected in the narratives of individuals learning how to cope with depression adequately. Systematic reviews show that similar strategies are used to cope with other (physical) chronic conditions (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002) and SMI (Beentjes, van Gaal, van Achterberg, & Goossens, 2020).

Second, empowerment is widely recognized as a key aspect for coping with, and recovery in (serious) mental illness (Boevink, Kroon, van Vugt, Delespaul, & van Os, 2016b; Davidson, O'Connell, Tondora, Lawless, & Evans, 2005b; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Slade et al., 2012; WHO, 2013). However, research on empowerment for depression specifically seems limited (Crisp, Griffiths, Mackinnon, Bennett, & Christensen, 2014; Nimrod, 2012a). The broad concept of empowerment include the living a meaningful life, according to one's own values (Boevink, Kroon, Delespaul, & Van Os, 2016b; Halvorsen et al., 2020). This is echoed in our qualitative data; participants explained that taking back control in their lives was crucial to manage the depression. Hence, empowerment seems relevant in the evolvement of experiential knowledge in depression specifically.

Additionally, we found that introspection encouraged individuals to learn how to live with depression. This may not be surprising as metacognitive reflection is crucial in psychotherapy as well (Lysaker, Hamm, Hasson-Ohayon, Pattison, & Leonhardt, 2018). Furthermore, self-reflection is implicitly mentioned in the first -but still principal- definition of experiential knowledge "the truth *learned from personal experience* with a phenomenon" (Borkman, 1976, p. 446), and is incorporated in recovery models as a stage, were contemplation (Leamy et al., 2011) and increased awareness of the self (Andresen, Oades, & Caputi, 2003) are discussed. However, the models do not explicitly mention how individuals experience and interpret these stages. Our data suggests that for introspection, adopting a mild attitude, and increased acceptance towards the depression, facilitates experiential knowledge on how to effectively deal with the illness. Future studies should explore the meaning of introspection in recovery for depression more explicitly.

Experiential Knowledge in Depression From a Recovery-Oriented Perspective

Overlooking the available literature on the abovementioned central themes for experiential knowledge in depression, at this point it seems that previous research primarily include patients with SMI (Thomas, Despeaux, Drapalski, & Bennett, 2018), focusing on psychotic disorders and schizophrenia (Boevink et al., 2016a; Boumans, Baart, Widdershoven, & Kroon, 2017; Castelein, Timmerman, van der Gaag, & Visser, 2021; Jääskeläinen et al., 2013; Roosenschoon, Kamperman, Deen, Weeghel, & Mulder, 2019). Moreover, these studies are mostly considered from a broader recovery-oriented perspective (Yanos, DeLuca, Roe, & Lysaker, 2020), including clinical, personal, and functional recovery (Leamy et al., 2011; Slade et al., 2012; Vogel et al., 2020; Whitley & Drake, 2010). In particular the aspects of personal recovery of the CHIME framework (e.g., connectedness and empowerment; Leamy et al., 2011) seem to correspond with themes of experiential knowledge for depression. Since CHIME is a guiding principle for a wide variety of mental illness, this suggests that there are universal applicable principles in coping with a mental disorder. It is therefore important to examine common and underlying transdiagnostic processes for experiential knowledge, as a relevant domain for the recovery-oriented approach.

Deploying Experiential Knowledge in Peer Support

Building on our general question in chapter 2, on how to cope with and develop experiential knowledge in depression, we evaluated if sharing such experiences in peer support is beneficial for individuals with depression. Below, we discuss our findings for the *effectiveness* of peer support (chapter 5) and its *potential working mechanisms*, focusing on online user engagement (chapter 3 and 4).

The Effectiveness in Peer Support

Previous systematic reviews and meta-analyses for peer support interventions (PSIs) showed that peer support for individuals with mental illness is effective for recovery-oriented outcomes, improving perceptions of *personal recovery* in general (Lyons, Cooper, & Lloyd-Evans, 2021; White et al., 2020) and specific components such as self-efficacy and hope (Bryan & Arkowitz, 2015; Burke, Pyle, Machin, Varese, & Morrison, 2019; Chien, Clifton, Zhao, & Lui, 2019; Fuhr et al., 2014; Huang et al., 2020; Lloyd-Evans et al., 2014). Yet, meta-analyses did not report a *clinically* important advantage over control conditions (Burke et al., 2019; Chien et al., 2019; Fuhr et al., 2014; Huang et al., 2020; Lloyd-Evans et al., 2014; Lyons et al., 2021; White et al., 2020), and outcomes for *functional recovery* such as social support are scarcely addressed so far (Fuhr et al., 2014; Lyons et al., 2021). These meta-analyses are limited to subgroups and the most comprehensive meta-analyses was conducted almost a decade ago (Lloyd-Evans et al., 2014).

Expanding the scope of previous systematic reviews and meta-analysis, we set out to investigate the effectiveness of engaging in PSIs across a wide range of mental illness, intervention types, and we pooled outcomes for both clinical, personal, and functional recovery. Our results showed that peer support has potential benefits across a wide range of mental illnesses for primarily clinical (i.e., symptomatic) and personal recovery, with probable efficacy for functional recovery at long-term. Although the effect sizes were small, they were consistent across the wide varying studies.

Patients with SMI, also including major depressive disorders, was the majority of participants in the included trials. This subgroup seemed to benefit the most. Engaging in a PSI was associated with superior outcomes across *all three* recovery domains at post-test. Though effect sizes were small, they might be of clinical and practical significance for the patient. First, since patients with SMI struggle with persistent symptoms and probably experience severe impairment in daily life, small improvements in recovery might be meaningful to them. Moreover, PSIs are generally implemented as an addition to professional treatment. Therefore, engaging in PSIs with a small effect can be seen as an additional benefit. It is important to realize that research on peer support is associated with methodological issues (e.g., at this point, it is not possible to establish model fidelity; Fortuna, Solomon, & Rivera, 2022) which limits the quality of studies. Therefore, our results should be interpreted with caution. Still, our meta-analytic results strengthen hypotheses raised in descriptive systematic reviews and user evaluation studies for PSIs, collectively presenting valuable experiences and benefits for peer support, including emotional support and hope (Chinman et al., 2014; Crisp & Griffiths, 2016; Fortuna et al., 2020; Griffiths, Calear, & Banfield, 2009a; Griffiths, Calear, Banfield, & Tam, 2009b; Jones, Jomeen, & Hayter, 2014; Moore, Drey, & Ayers, 2020; Pitt et al., 2013; Shalaby & Agyapong, 2020; Walker & Bryant, 2013). Additionally, we extend previous findings that engaging in peer support is potentially effective for personal recovery (Lyons et al., 2021; White et al., 2020), indicating that peer support may be effective for clinical recovery as well.

Mechanisms of Peer Support

Additionally, we explored the naturally occurring mechanisms underlying changes for recovery in online peer support to better understand how PSIs work. In a broad and recent systematic review (Winsper, Crawford-Docherty, Weich, Fenton, & Singh, 2020), including 309 studies on recovery-oriented interventions for mental illness, four common processes fostering change for recovery were identified: (a) providing information and skills; (b) promoting a working alliance; (c) role modelling for individual recovery; and (d) increasing choice and opportunities (Winsper et al., 2020). These processes may best be initiated within non-stigmatized recovery-focused contexts, such as peer support were psychosocial processes of sharing lived experiences, emotional honesty, strengths-focused social and practical support, and the helper-role are important processes for mental health recovery (Watson, 2017). Our qualitative evaluation study for users of the online peer support community DC, described in chapter 3, fit with these processes. Users describe that engaging in peer support is perceived helpful to connect with others (corresponding to the factors social support and emotional honesty; Watson et al., 2017). Also, DC-users benefited since they felt valuable to others by supporting peers with their own lived experience, making sense of their depression and transforming negative experiences into valuable knowledge which may be beneficial for other individuals coping with depression (corresponding to the helper-role; Watson et al., 2017). It should be noted that these benefits focus on an online format of peer support, and probably only refer to high or active users, which is generally a small group in online communities (Carron-Arthur, Cunningham, & Griffiths, 2014). Yet, this relatively new format of digital peer support has become increasingly relevant during the COVID-19 pandemic and its working mechanisms need further research.

Online Peer Support as a Learning Environment. Furthermore, we extended previous findings because we unexpectedly found that the online peer support community DC served as a safe space to practice (social) skills for the offline world, here referred to as *learning environment*. For example, DC-users try to be open on the online platform about the illness and the difficulties in living with depression, subsequently finding courage to disclose their issues during face-to-face interactions in their offline social network. This echoes the principles of a “Community of Practice”, a well-known learning theory (Lave & Wenger, 2004), implying that a social community where members interact and participate actively is a breeding ground where dynamic processes of learning naturally unfold (Schwandt, 2001).

Reconsidering the central themes identified for the evolvement of experiential knowledge in chapter 2 (i.e., self-management strategies, introspection, and empowerment), we hypothesize that these themes are potentially related to the benefits of peer support that we identified in chapter 3 (i.e., connecting to others, emotional growth, self-efficacy, and empowerment). Together with the idea that peer support provides users a safe learning environment, this might indicate that PSIs facilitate the cyclical process of developing experiential knowledge: a place where self-management could be practiced, and emotional growth and skills for empowerment may be facilitated.

Last, the qualitative data of DC-users tentatively indicated a development of user roles, users seemed to progress from passive readers to active users: sharing own stories or questions, and helping others. This might reflect a start for shifting individual experiential knowledge to collective experiential knowledge. According to the theory of “Deep Experiential Knowledge”, sharing and listening to stories is the fundament of developing a common understanding of a mental health issue (Noorani, Karlsson, & Borkman, 2019). In peer support individuals may learn by together building “meaning perspectives”, referring to the collective challenges, potential workable and unworkable strategies for coping with the illness. The presence of role models or long-term members is crucial to encourage sharing, and they may evolve into “experts-by-experience” when she or he is able to translate the personal experience into helpful knowledge for peers (Kirkegaard, 2022; Mazanderani, Noorani, Dudhwala, & Kamwendo, 2020). Again, it is important to realize that these processes may unfold for a limited group of active or high users in PSIs. Last, increased risks for actively and passionately engaging in peer support should be considered as users might self-identify with the helper-role too much.

Which Types And Intensity of User Engagement Foster Change?

The abovementioned mechanisms underpinning recovery-oriented practice, and more specifically peer support should be examined in the context of the service: What elements are needed? Since self-determination is a crucial aspect of the recovery-oriented approach, voluntary use of the program seems important (Solomon, 2004). This thesis explores the nature and intensity of user engagement in online peer support, with potential links to recovery benefits. As such, we add to the current ambiguous knowledge base on user engagement (Carron-Arthur, Ali, Cunningham, & Griffiths, 2015).

In the longitudinal quantitative data collected at our online peer support community for depression, described in chapter 4, we did not find a significant relation between the intensity level of user engagement at DC and the increased levels for empowerment, self-management, and reduced depressive symptoms and disability. Previous reviews emphasize the variety of user engagement styles and intensity levels (Carron-Arthur et al., 2015; Fortuna et al., 2020). We suggest, with regard to user engagement mode, that it might be too simplistic to assume that there is one optimum engagement intensity level or participation style. Corresponding to the self-determination theory (Deci & Ryan, 1985), findings for our PSI suggest that the autonomy to choose the intensity level and participation style in peer support according to one’s own needs in the recovery process is considered an essential element of the service. Feeling in control (i.e., autonomy to choose) may be a condition for self-development for the participant, which is also suggested in the recent peer support review of Fortuna and colleagues (2022).

However, in contrast to the potential benefits of flexible usage, there is substantial evidence that high (i.e., intensive) usage and structure is needed to benefit from mental health care services, including eHealth (Geramita et al., 2018; Hensel et al., 2019), and Cognitive Behavioral Therapy (Cuijpers, Noma, Karyotaki, Cipriani, & Furukawa, 2019). This suggests that a certain amount of structure and intensity level of use would improve the efficacy for peer support. In contrast, in our meta-analysis, no differences in effect was detected for structured versus unstructured peer support formats.

Together, it is important to shed more light on user engagement processes in peer support, including the optimum guidance and structure level. This may improve our understanding of the mechanisms behind peer support, and to improve its efficacy by potentially serving as a learning environment.

In sum, integrating the results for the qualitative studies, the user survey, and meta-analyzing empirical evidence for peer support, both experiential knowledge and peer support are probably relevant for recovery in mental illness, and depression specifically. More research is needed to gain insight in the processes behind peer support that may foster change, including modes of user engagement. The potential benefits for experiential knowledge and peer support fit to the tendency in mental health care to strengthen the community around the individual person that is seeking help, for example by the implementation of resource groups (Tjaden et al., 2021), and in broader context often referred to as the ecosystem approach (Furst, Bagheri, & Salvador-Carulla, 2021; WHO, 2021).

Strengths and Limitations

One major strength of this thesis is the use of different methods. The qualitative study for experiential knowledge in **chapter 2** provides an in-depth description of patient's experiences on coping with depression. This informed us that the processes on learning how to cope with depression are complex and cyclical, though universal applicable principles are recognized. However, generalizability is limited since we focused on individuals with longer-term depression, participating in mental health care. **Chapter 3**, the qualitative evaluation study of peer support, gives insight in the processes for user engagement styles that might foster change in recovery for individuals with depression. However, the decision to participate in this study may have reached high users only, with a positive bias towards engaging in peer support. Also, the fact that the study was conducted during the COVID-19 pandemic might have caused the results to be biased in a positive direction. Since face-to-face contact was restricted during this time period, the importance of online types of support for depression increased. Nevertheless, this study generated hypotheses for modes of user engagement and related benefits. The longitudinal user survey in **chapter 4** broadened our view on levels of user engagement in online peer support in a bigger sample of individuals with depression. The majority of participants were Dutch and highly-educated, and received support from a mental health care service, limiting generalizability. However, a naturalistic sample was used to represent a general and heterogeneous population of individuals with depression, engaging in peer support. The user survey was exploratory, we could not incorporate a control group which hampers analysis for (causal) relationships between user engagement and the recovery outcomes. We examined comprehensive outcomes, such as empowerment, a concept that includes many aspects for recovery. Since it is generally known that high and long-term user engagement in online peer support is very limited (Van Mierlo, 2014), narrow outcomes such as hope are potentially more feasible (Fortuna et al., 2022). The significant effect size for hope in our meta-analysis confirms this hypothesis. With regard to the operationalization for user engagement, it was not possible to capture all relevant factors for this concept quantitatively. Potentially relevant indicators for engagement, such as the content of posts (Takahashi et al., 2009) and the number of replies received (Lee, Yang, & Rim, 2014; Pan, Feng, & Shen, 2020) were not included. In the meta-analysis presented in **chapter 5** we pooled the most trials to date for peer support across a wide range of mental illnesses, and as such found evidence for the effectiveness of peer support across three recovery categories. The low heterogeneity across the included trials suggested that the significant effects were consistent, primarily providing robust evidence for clinical recovery. It should be considered that the measures for recovery differed across the studies, and that subgroup analyses were limited to smaller samples. A major limitation is the high risk of bias for the majority of the included trials, which is a common issue for peer support studies.

Collectively, using multiple methods (including qualitative, quantitative, and meta-analytic designs) we attempted to capture the complexity of experiential knowledge and peer support in depression and mental health recovery. A major strength of this thesis is that, throughout the entire course of the research project, we conducted the research in a unique collaboration with the national patient association for depression: the Dutch Depression Association. As such, including the patient perspective was not limited to study participants. Bringing individual experiences and different perspectives together gave us the opportunity to create new hypotheses, which were further examined quantitatively to work towards a collective understanding for experiential knowledge and peer support for recovery in depression.

Future Directions

Further Research

Primarily, this thesis has an explorative character and is not intended to give definite answers but raises questions for further research. Below, we suggest how to address three relevant issues in this research field.

First, whilst there is growing evidence for the benefits and effectiveness of peer support, its working mechanisms as well as the (sequential or bi-directional) relation between recovery processes remain unclear (e.g., employment might increase self-esteem, which may in turn contribute to functional recovery; Whitley & Drake, 2010). A nested mixed-method effectiveness study providing evaluation of processes along with qualitative and quantitative outcomes should further address this issue. Combining multiple data sources in this method may facilitate a good balance between explorative and more systematic research. For example, as a first step, the study of a particular case engaging in peer support, including the complexity, may help to understand what factors are relevant for recovery and how they are addressed in peer support settings. Second, quantitative components could help assessing the effectiveness, its magnitude and potentially enhances generalization of the results. Including a comparison group would improve the results with the possibility for tentative causal interpretation. However, the fact remains that there are a lot of unknown and undefined variables associated with engaging in peer support (e.g., subjective experiences of online contact, self-stigma, and phase of the illness). These factors potentially bias the results and cannot be controlled for. Yet, including multiple methods can yield rich and comprehensive data and thus provide a more holistic view on how people cope with and recover in depression with the support from peers.

Second, a key challenge is to determine whether online supported processes for recovery, including skills learned and practiced online with peers, are deployed in offline social networks (without peers), and as such contribute to mental health recovery in the offline world. To address and evaluate this “online-to-offline” and “peer-to-non-peer” transfer by including factors for functional recovery, the perspective of the significant other in the recovery pathway could be included in future studies. A relative might encourage the patient using online peer support to engage in their mutual offline social network as well. Furthermore, supporting and subsequently evaluating levels for social and societal participation (e.g., work, study, or other relevant daily activities; Whitley & Drake, 2010) when engaged in online peer support might give insight in the “online-to-offline” transfer. To capture the potential erratic course of functional recovery (Castelein et al., 2021; Green, Kern, & Heaton, 2004; Jääskeläinen et al., 2013), frequent and longitudinal assessment on outcomes for this recovery domain seems needed.

Third, although peer support is developing worldwide, there is not much known about the experience of peer support across different cultures. The WHO (2021) calls for peer support as a low-cost, accessible, and community-based service to improve mental health services around the world (WHO, 2021). Mental illnesses and health services are differently expressed and understood across cultures (Carpenter-Song et al., 2010), and social networks function differently. For example, with the Ubuntu philosophy in Africa, living in a community is more important (Nussbaum, 2003) than in the individually focused Western world (Panter-Brick & Eggerman, 2012). Therefore, ethnicity and culture probably plays an important role in the experiences and effectiveness of peer support and should be addressed in future studies.

Taken together, it is of major importance in studies for recovery to actively seek a balance between an explorative perspective that generates hypotheses and more systematic research, testing those hypotheses. On the one hand the uniqueness and flexibility of engaging in peer support fits the explorative perspective. On the other hand, systemizing essential elements of the peer support intervention (e.g., content, structure, guidance, participation level) may help to assess effectiveness. It is needed to quantify factors related to recovery to allow for uniform, valid and reliable research that offers the possibility to delineate the effectiveness of peer support and the course of recovery longitudinally.

Implications For Clinical Practice

Several clinical implications could be derived from this thesis. First, the conceptual framework for experiential knowledge provide clinical practitioners with an overview for relevant processes for the individual in recovery. Professionals could, together with the patient, explore what introspection, empowerment, and self-management mean to the individual with depression and what circumstances are needed to develop these skills. As such, setting goals for recovery together might enhance therapeutic alliance (Osborn & Stein, 2019).

Secondly, the findings of our studies suggest that peer support may serve as a valuable and effective additional service in the recovery pathway. The user experiences and meta-analytic evidence described in this thesis present promising results for clinical and personal recovery at short-term. Together with the potential low-cost of PSIs and the assumption that peer support may be relatively easy to organize, this evidence supports funding for PSIs for individuals with mental illness. The availability of peer support could be increased by incorporating PSIs as a supplement to routine care practice. Furthermore, peer support services of patient organizations and local recovery initiatives might be expanded, further improved and disseminated. For the latter two stakeholders (i.e., patient organizations and recovery initiatives), experiential knowledge is considered a valuable knowledge base and peer-to-peer interactions are facilitated by their services though resources are generally limited in these organizations. With regard to mental health care services, an overview of peer support and recovery initiatives may be helpful for the professional when they want to refer patients. Also, engaging experiential experts as part of the treatment team in mental health care services may help to incorporate experiential knowledge.

Third, when considering these implications, the balance between experiential-, professional-, and scientific knowledge should be considered. Sackett's definition for Evidence Based Practice (EBP) requires "the integration of the best *research evidence* with our *clinical expertise* and our *patient's unique values* and circumstances" (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). Hence, the three knowledge bases are intended to mutually reinforce one another, and should not be hierarchical presented to the individual living with the illness. With the support of evidence-based treatment (scientific knowledge), the professional should encourage the individual with depression to progress and manage their personal recovery pathway (professional knowledge), where the patient develops experiential knowledge on how to cope with depression following personal needs and preferences for self-management strategies (experiential knowledge). In this triangular relationship, the parties can learn from each other's concepts, and together find a common language to understand each other.

Overall, at a national level, a better collaboration between mental health care institutions, national patient organizations, and local recovery initiatives in the social domain may improve the position of experiential knowledge and peer support in the Dutch landscape. Co-creations between these stakeholders may help to develop organization-exceeding innovations, leading to small but potential relevant contributions to the societal issue for depression as a leading cause of disability (WHO, 2017).

Conclusions

We focused on, found evidence for, and raised questions at a micro-level for experiential knowledge and peer support. From this thesis, it can be concluded that sharing experiential knowledge through engaging in online peer support is a beneficial experience for individuals with depression. The intensity and nature of online user engagement varies between individuals and during the course of the recovery pathway. The possibility to adapt engagement to one's personal needs in coping with the illness might be a relevant feature of online delivered peer support. At a meso-level, experiential knowledge should be acknowledged and implemented in research and clinical practice as a valuable knowledge base. Since peer support is effective across domains for clinical, personal, and functional recovery, professionals may refer their clients to peer support. It may be an accessible, low-cost, and evidence-based service to integrate in mental health care. Its implementation should be supported at a macro-level.

Future research on recovery and online peer support in depression should address underpinning processes that foster change, including processes and outcomes for functional recovery. Central to this domain, exploring how online learned skills could be transferred to offline, real-world settings might be a first step. Mixed methods should be used to capture the complexity of recovery pathways including the use of experiential knowledge and peer support.

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Research Data Management

This project is conducted in an external PhD studentship of the mental health care institution Pro Persona and the Radboud University. In accordance with the research data management policy of the Radboud University (https://www.ru.nl/rdm/) and the Behavioral Science Institute (BSI), all research data were stored and archived meeting the (inter)national standards, following the BSI's General Data Protection Regulations (GDPR; https://www.radboudnet.nl/bsi/procedures/bsi-specific/gdpr/). After considering the ethics in this project, we explain how we adhered to the FAIR principles (Findable, Accessible, Interoperable, Reusable), aimed to enhance open science and transparent research practices.

Ethics

This thesis consists of studies with human participants, which were conducted in accordance with the principles of the Declaration of Helsinki. The Ethical Committee [Commissie Mensgebonden Onderzoek region Arnhem-Nijmegen] deemed ethical approval not necessary given the minimal burden to study participants. Though, to follow ethical principles and to guarantee our participants confidentiality, we followed the Good Clinical Practice guideline, which is the fundament for the procedures at the mental health care institution Pro Persona.

Findable, Accessible

All published chapters are registered on the Research Information Services (RIS) of the Radboud Data Repository (RDR). The Netherlands Code of Conduct for Research Integrity[a] requires researchers to make data as open as possible after publication. Since the data for both qualitative studies (chapter 2 and 3) are highly sensitive, we cannot share the data without breaking ethical rules and the confidentiality that we guaranteed to our participants. For chapter 4, we stored the study material and approaches for this chapter as open as possible, and as closed as necessary at the RDR (https://doi.org/10.34973/x31b-2k84). We preregistered our systematic review and meta-analysis presented in chapter 5 at Open Science Framework (OSF) (https://osf.io/58urb). The data and analyses scripts will be available at request.

Interoperable, Reusable

Regarding the studies in chapter 2 and 3, data could not be de-identified and stored in a digital repository. For chapter 4 and 5, we used long-lived file formats to ensure usable data in the future (e.g., .sav, .txt). We added readme files explaining the structure and content of the shared documents. All data archived remain available for at least 10 years after termination of the studies.

[a] Algra, K. A., Bouter, L. M., Hol, A. M., & van Kreveld, J. (2018). Nederlandse gedragscode wetenschappelijke integriteit.

Appendices

Overview Appendices

Chapter 2 Appendix A

Interview Guide for the Research Article: An Exploration of The Conditions For Deploying Self-Management Strategies: a Qualitative Study of Experiential Knowledge in Depression

Main topic	***Specific aim/question***
Introduction	Introduce yourself (the researcher) Explain • the rationale and objectives of the study (and research project) • anonymity, confidentiality, voluntary participation; possibility to ask for a recess or end the interview at any time • your role as researcher • audio recording • expected duration: 45 minutes • informed consent
Background	Screening and brief synopsis of the interview Any questions/comments?
Course of depression	*Can you tell me something about the course of your depression?* • Start • Triggers/process • Current state of mind • Current therapy
Questions per topic on coping with depression	

The self	• What was helpful in coping with depression?
	    • Personal characteristics
	    • Activities, daily structure
	    • Asking for help
	    • Acknowledging the problem
	    • Triggers/signals
	• In your experience, what is the role of self-reflection in coping with depression?
	• Can you describe your attitude towards depression?
	    • Did your attitude change over the course of time, with regard to acceptance?
	• Do you experience different phases in coping with depression?
	• What did you need to deploy self-management strategies?

Gaining insight	- *Did you change your way of managing depression over the course of the illness?*
	- *What contributed to the development of personal fitting coping strategies?*
	- *What was helpful to gain insight in your (behavior and/or thought) patterns?*
	  - The role of mental health care in gaining insight
	  - Changes in coping with depression after these new understanding
	- *According to your experience, in what manner is experiential knowledge of coping with depression developing?*

Environment	- What did you learn from others about coping with depression?
	- What is the role of your social network in coping with depression?
	  - Family/friends
	  - Work
	  - Peer support
	  - Societal context
	- In what manner did your social network help you when coping with depression?
	  - What would have helped?
	  - What was not helpful?

Religion/ spirituality	- What is the role of religion or spirituality in coping with depression for you?
	  - Existential questions
	  - Giving meaning

Professional help	- In your experience, what is the role of professional help in coping with depression?
	  - Mental health care, therapy
	  - Medication
	  - Counselling
	  - Alternative therapies
	  - Follow-up care

Role of depression in life	- *What are positive and negative aspects of suffering from depression, in your experience?*

Experiential expertise	• What is your opinion about experiential expertise of depression?
	    • Personal experience of being counselled by an experiential expert
	    • Role of the patient organisation: Dutch Depression Association
	• Risks versus added value of experiential expertise in mental health care for depression

Concluding the interview	• Do you have anything to add to this conversation? • Did we miss something, topics that we did not discuss, but are important to you in coping with depression?

Chapter 2 Appendix B

Telephone Screening for the Research Article:
An Exploration of The Conditions For Deploying Self-Management Strategies: a Qualitative Study of Experiential Knowledge in Depression

Date of screening:	
Introduction	
• *Introducing yourself: junior researcher at Pro Persona Research & Radboud University Nijmegen* • *Explain the aim of the research "The Power of Depression"* • *Explain the aim of the interview about experiential knowledge of depression* • *Explain the aim of this telephonic screening:* 1. *Inventory of the characteristics of the research sample* 2. *Personal questions about the course of suffering from depression* 3. *Transformation into anonymous data* 4. *Carefully handling this confidential information* • *Explain the aim of the MINI-interview* 1. *Checking mental health issues, inclusion- and exclusion criteria* 2. *Structured interview* • *Questions?*	
Personal details	
What is your date of birth?	
What is your cultural background?	
Country of birth:	
Country of birth mother:	
Country of birth father:	
Educational level (completed)	
Gender	
Details about the course of depression	
In what year did you experience your first depressive episode?	
How many depressive episodes did you experience?	
When did you experience your last episode?	
Do you suffer from depression at the moment?	
Did you receive treatment for mental health issues?	
Are you currently in therapy? If so: What kind of therapy do you receive?	
Do you currently use medication?	

Conducting MINI interview (Sheehan et al., 2006)

For the full version of the Mini International Psychiatric Interview for DSM-IV-TR (standardised clinical diagnostic interview) see: Sheehan, D. V., Janavs, J., Baker, R., Sheehan, K. H., Knapp, E., & Sheehan, M. (2006). The Mini-International Neuropsychiatric Interview (MINI) English Version 5.0. 0. DSM-IV. Tampa, FL: University of South Florida.

Completion of telephone screening; Thank you for your answers.

Does participant meet the inclusion- and exclusion criteria?

→ *No: explain why and thank respondent for participating this far*
→ *Maybe: explain why, discuss with colleagues and call back later*
Yes: schedule an interview with respondent

Chapter 3 Appendix

Interview Guide for the Qualitative Evaluation of the Online Peer Support Community Depression Connect (DC)

Dorien Smit and Amber Dings	
Main topic	***Specific aim/question***
Introduction	Introduce yourself (the researcher) Explain • the rationale and objectives of the study (and research project) • anonymity, confidentiality, voluntary participation; possibility to ask for a recess or end the interview at any time • your role as researcher • audio recording • expected duration: 45 minutes • informed consent
Background	Screening and brief synopsis of the interview Any questions/comments?
Reasons for signing up with DC	When and why did you subscribe to DC? What was your aim when you first joined DC?
Forum use in general	In general, **when** do you use the forum, **why**, i.e. with what **objective**? *For example: did you have a specific question/need for information or simply out of general interest?*

Merits **Participation style(s)**	Can you give an **example** when you benefited from forum use? When is the forum (most) useful? • For **what** goals • **When** (under which circumstances) • In **which state of mind**? In a more critical and/or stable phase of depression? Why opt for this online forum; in what way(s) does it **differ** from other options *(e.g. professional help, social support in daily life)*? How would you describe the **usefulness** of the messages of other users? Do you think/feel you can **help or support** other DC-users? Would you recommend DC and, if so, to **whom** would you recommend it? **Personal/functional/clinical recovery:** To what extent do you benefit from DC in coping with your depression on a daily basis?
Demerits	Can you give an example when you did not benefit from the forum? **When,** for **whom** or under **which circumstances** is the forum **not useful?** **Why?**
Current role/ relevance of DC	What is the role/relevance of DC in your life at this moment?
Role DC in relation to other means of (in)formal support	What is the role of DC in relation to other informal support and/or formal care for depression? • Social network • Mental health care (psychological/psychopharmacological treatment) • Live peer support Have you benefited from DC-use in ways you had not expected?
Open question	Do you have something to add, topics we did not discuss that you think are relevant to characterize the (dis)advantages of Depression Connect?
Concluding the interview	Are you willing to participate in an interim assessment and provide feedback on the interim results? Thank the participant for his/her contributions

Chapter 4 Appendix

Table. *Baseline Demographics and Clinical characteristics for The Total Study Group and for the four Engagement Profiles at DC*

Characteristic		**Engagement Profile**					
	Total study group (N = 301)	***Very Low* Engagement (profile 1) (*n* = 177)**	***Low* Engagement (profile 2) (*n* = 87)**	***Medium* Engagement (profile 3) (*n* = 30)**	***High* Engagement (profile 4) (*n* = 7)**	**Test Statistic**	
	***M* (*SD*) or frequency (%)**	***M* (*SD*) or frequency (%)**	***M* (*SD*) or frequency (%)**	***M* (*SD*) or frequency (%)**	***M* (*SD*) or frequency (%)**	***F(df)* or $\chi^2(df)$**	***p***
Age in years (range 18-99), *M* (*SD*) [a]	50.2 (13.12)	50.49 (13.15)	48.33 (13.35)	52.42 (13)	57.33 (5.41)	F(3,295) = 1.59	.19
Female, *n* (%)	199 (66.1)	114 (57.3)	63 (31.7)	18 (9)	4 (2)	$\chi^2(3) = 2.5$	.47
Current depression (self-reported), *n* (%) [b]	216 (73.2)[b]	123 (56.9)	69 (31.9)	21 (9.7)	3 (1.4)	$\chi^2(3) = 5.1$	.16
Current treatment, *n* (%) [c]	203 (67.4)	118 (58.1)	61 (30)	22 (10.8)	2 (1)	$\chi^2(3) = 0.6$	.13
Current antidepressant medication, *n* (%)	210 (69.8)	130 (61.9)	59 (28.1)	17 (8.1)	4 (1.9)	$\chi^2(3) = 4.3$	.23
Empowerment (NEL), *M* (*SD*) at baseline	2.06 (.51)	2.04 (0.5)	2.07 (0.55)	2.09 (0.45)	2.23 (0.32)	F(3,297) = 0.42	.74
Self-management (ASAD), *M* (*SD*) at baseline	78.11 (25.07)	78.87 (25.1)	75.59 (25.21)	80.6 (25.57)	79.57 (23.41)	F(3,297) = 0.45	.72
Functioning and Disability (WHODAS 2.0), *M* (*SD*) at baseline	35.7 (15.3)	36.49 (15.79)	34.73 (15.29)	34.04 (13.13)	35.17 (13.03)	F(3,297) = 0.39	.76
Depressive symptoms (BDI-II), *M* (*SD*) at baseline	29.84 (11.85)	30.24 (12.5)	29.34 (11.24)	30.07 (10.71)	25 (6.43)	F(3,297) = 0.51	.68
Completers (2 or 3 assessments), *n* (%)	122 (40.5)	60 (34)	33 (37.9)	22 (73.3)	7 (100)	$\chi^2(3) = 27.14$	<.001

Note. Abbreviations: ASAD = Assessment of Self-management in Anxiety and Depression questionnaire; BDI = Beck Depression Inventory; DC = Depression Connect; *M* = Mean; NEL = Netherlands Empowerment List; *SD* = Standard deviation; WHODAS =, World Health Organization Disability Assessment Schedule.

[a] Due to 2 missing variables, *n* = 299 for the total group, *n* = 176 for profile 1; *n* = 86 for profile 2; *n* = 30 for profile 3; *n* = 7 for profile 4

[b] Due to 6 missing variables, *n* = 295 for the total group, *n* = 174 for profile 1; *n* = 85 for profile 2; *n* = 30 for profile 3; *n* = 6 for profile 4

[c] Includes any mental health care (e.g., general or specialized mental healtht care, and alternative support)

Chapter 5 Appendix A

Complete search strings per database (PubMed, Embase, and PsycINFO)

Search string used for PubMed, with keywords:
Block 1: Peer support;
Block 2: Mental health illness;
Filter: RCTs.

Block 1:
((Peer*[tiab] OR buddy[tiab] OR buddies[tiab] OR “mutual help”[tiab] OR “mutual support”[tiab] OR “social support”[tiab] OR “Peer-based*”[tiab] OR “Peer support*”[tiab] OR “Peer-led*”[tiab] OR “Peer-provided*”[tiab] OR “Peer-run*”[tiab] OR “Peer to peer*”[tiab]) AND (intervent*[tiab] OR therap*[tiab] OR coach*[tiab] OR counsel*[tiab] OR program*[tiab] OR service*[tiab] OR “Self-help group*”[tiab])) OR “Mutual Support*”[tiab] OR “Mutual help*”[tiab] OR “Shared medical appointment*”[tiab] OR “Patient to patient*”[tiab] OR “Peer self-management*”[tiab] OR “Support group*”[tiab] OR “Support program*”[tiab] OR “Support intervention*”[tiab] OR ((online[tiab] OR internet*[tiab]) AND (forum[tiab] OR group[tiab] OR communit*[tiab] OR discussion[tiab] OR board[tiab]) AND (support[tiab] OR “mutual help”[tiab] OR “peer”[tiab] OR “buddy”[tiab] OR “buddies”[tiab])) OR ((“Self-help groups”[MeSH] OR “Self-management”[MeSH]) AND (“Peer”[tiab] OR buddy[tiab] OR buddies[tiab] OR “mutual help”[tiab] OR “mutual support”[tiab]))

AND

Block 2:
“mental health*”[tiab] OR “Mental Health”[Mesh] OR “mental disorder*”[tiab] OR “Mental disorders”[Mesh] OR “mental diagnos*”[tiab] OR “mental symptom*”[tiab] OR “mentally ill*”[tiab] OR “mental illness*”[tiab] OR “mental problem*”[tiab] OR “mental disease*”[tiab] OR “psychological disorder*”[tiab] OR “psychological symptom*”[tiab] OR “psychological diagnos*”[tiab] OR “psychological illness*”[tiab] OR “psychological disease*”[tiab] OR “psychological problem*”[tiab] OR “psychological patient*”[tiab] OR “Psychiatric symptom*”[tiab] OR “psychiatric disorder*”[tiab] OR “psychiatric diagnos*”[tiab] OR “psychiatric illness*”[tiab] OR “psychiatric disease*”[tiab] OR “psychiatric problem*”[tiab] OR “psychiatric patients”[tiab] OR “behavioural disorder*”[tiab] OR “behavioral disorder*”[tiab] OR “behaviour disorder*”[tiab] OR “behavior disorder*”[tiab] OR “psychological distress*”[tiab] OR “Mental distress*”[tiab] OR “Mentally distress*”[tiab] OR “Mentally Ill Persons”[Mesh] OR “Axis I disorder*”[tiab] OR “Axis 1 disorder*”[tiab] OR “affective disorder*”[tiab] OR “anxiet*”[tiab] OR “agoraphob*”[tiab] OR “neurotic

disorder*"[tiab] OR "obsessive compulsive*"[tiab] OR "ocd"[tiab] OR "panic*"[tiab] OR "phobi*"[tiab] OR "gad"[tiab] OR "bipolar*"[tiab] OR "eating disorder*"[tiab] OR "anorexi*"[tiab] OR "Bulimi*"[tiab] OR "Mood disorder*"[tiab] OR "depress*"[tiab] OR "dysthym*"[tiab] OR "personality disorder*"[tiab] OR "psychotic*"[tiab] OR "psychosis*"[tiab] OR "schizophren*"[tiab] OR "psychosis"[tiab] OR "somatoform disorder*"[tiab] OR "trauma*"[tiab] OR "posttraumatic stress"[tiab] OR "post-traumatic stress" OR "ptsd"[tiab]

With filter for RCTs

<u>Search string used for PsycINFO, with keywords [a]</u>
Block 1: Peer support;
Block 2: Mental health illness;
Filter: RCTs.

[a] *The double quotations (") need to be entered in the search box at the PsycINFO website. These characters cannot be copy-pasted from a text document into the online search box because quotations are changed to italic characters.*

Block 1:
((Peer*.ti,ab. OR buddy.ti,ab. OR buddies.ti,ab. OR "mutual help".ti,ab. OR "mutual support".ti,ab. OR "social support".ti,ab. OR "peer-based*".ti,ab. OR "peer support*".ti,ab. OR "Peer-led*".ti,ab. OR "Peer-provided*".ti,ab. OR "Peer-run*".ti,ab. OR "Peer to peer*".ti,ab.) AND (intervent*.ti,ab. OR therap*.ti,ab. OR coach*.ti,ab. OR counsel*.ti,ab. OR program*.ti,ab. OR service*.ti,ab. OR "Self-help group*".ti,ab.)) OR
"Mutual Support*".ti,ab. OR "Mutual help*".ti,ab. OR "Shared medical appointment*".ti,ab. OR "Patient to patient*".ti,ab. OR "Peer self-management*".ti,ab. OR "Support group*".ti,ab. OR "Support program*".ti,ab. OR "Support intervention*".ti,ab.
OR ((online.ti,ab. OR internet*.ti,ab.) AND (forum.ti,ab. OR group.ti,ab. OR communit*.ti,ab. OR discussion.ti,ab. OR board.ti,ab.) AND (support.ti,ab. OR "mutual help".ti,ab. OR "peer".ti,ab. OR "buddy".ti,ab. OR "buddies".ti,ab.))
OR ((exp Social Support/ or exp Support Groups/ or exp Self-Help Techniques/ or exp Social Support/ or exp Support Groups/ or exp Online Community/ or exp Online Social Networks/ or exp Group Discussion/ or exp Social Groups/ or exp Social Group Work/ or exp Self-Management/) AND (exp Peers/ or Peer*.ti,ab. OR buddy.ti,ab. OR buddies.ti,ab. OR "mutual help".ti,ab. OR "mutual support".ti,ab.))

AND

Block 2:
exp Mental Health/ or exp Mental Disorders/ or exp Chronic Mental Illness or exp Psychiatric Patients/ or exp Psychiatric Symptoms/ or exp Personality Disorders/ or exp Psychodiagnosis/ or exp Mood Disorder/ or exp Psychopathology OR mental health*.ti,ab. OR mental disorder*.ti,ab. OR mental diagnos*.ti,ab. OR mental symptom*.ti,ab.

OR mentally ill*.ti,ab. OR mental illness*.ti,ab. OR mental problem*.ti,ab. OR mental disease*.ti,ab. OR psychological disorder*.ti,ab. OR psychological symptom*.ti,ab. OR psychological diagnos*.ti,ab. OR psychological illness*.ti,ab. OR psychological disease*. ti,ab. OR psychological problem*.ti,ab. OR psychological patient*.ti,ab. OR Psychiatric symptom*.ti,ab. OR psychiatric disorder*.ti,ab. OR psychiatric diagnos*.ti,ab. OR psychiatric illness*.ti,ab. OR psychiatric disease*.ti,ab. OR psychiatric problem*.ti,ab. OR psychiatric patients.ti,ab. OR psychological distress*.ti,ab. OR Mental distress*. ti,ab. OR Mentally distress*.ti,ab. OR Axis I disorder*.ti,ab. OR Axis 1 disorder*.ti,ab. OR affective disorder*.ti,ab. OR anxiet*.ti,ab. OR agoraphob*.ti,ab. OR neurotic disorder*. ti,ab. OR obsessive compulsive*.ti,ab. OR ocd.ti,ab. OR panic*.ti,ab. OR phobi*.ti,ab. OR gad.ti,ab. OR bipolar*.ti,ab. OR eating disorder*.ti,ab. OR anorexi*.ti,ab. OR Bulimi*. ti,ab. OR Mood disorder*.ti,ab. OR depress*.ti,ab. OR dysthym*.ti,ab. OR personality disorder*.ti,ab. OR psychotic*.ti,ab. OR psychosis*.ti,ab. OR schizophren*.ti,ab. OR psychosis.ti,ab. OR somatoform disorder*.ti,ab. OR trauma*.ti,ab. OR posttraumatic stress.ti,ab. OR post-traumatic stress.ti,ab OR ptsd.ti,ab.

With filter for clinical trials

<u>Search string used for Embase, with keywords:</u>
Block 1: Peer support;
Block 2: Mental health illness;
Filter: RCTs.

Block 1:
((Peer*:ti,ab OR buddy:ti,ab OR buddies:ti,ab OR 'mutual help':ti,ab OR 'mutual support':ti,ab OR 'social support':ti,ab OR 'Peer-based*':ti,ab OR 'Peer support*':ti,ab OR 'Peer-led*':ti,ab OR 'Peer-provided*':ti,ab OR 'Peer-run*':ti,ab OR 'Peer to peer*':ti,ab) AND (intervent*:ti,ab OR therap*:ti,ab OR coach*:ti,ab OR counsel*:ti,ab OR program*:ti,ab OR service*:ti,ab OR 'Self-help group*':ti,ab)) OR 'Mutual Support*':ti,ab OR 'Mutual help*':ti,ab OR 'Shared medical appointment*':ti,ab OR 'Patient to patient*':ti,ab OR 'Peer self-management*':ti,ab OR 'Support group*':ti,ab OR 'Support program*':ti,ab OR 'Support intervention*':ti,ab OR ((online:ti,ab OR internet*:ti,ab) AND (forum:ti,ab OR group:ti,ab OR communit*:ti,ab OR discussion:ti,ab OR board:ti,ab) AND (support:ti,ab OR 'mutual help':ti,ab OR 'peer':ti,ab OR 'buddy':ti,ab OR 'buddies':ti,ab))
OR (('Self care'/exp OR 'psychosocial care'/exp OR 'self help'/exp) AND ('Peer':ti,ab OR buddy:ti,ab OR buddies:ti,ab OR 'mutual help':ti,ab OR "mutual support":ti,ab))

AND

Block 2:
‘mental health*’:ti,ab OR ‘mental health’/exp OR ‘mental disorder*’:ti,ab OR ‘mental disease’/exp OR ‘mental diagnos*’:ti,ab OR ‘mental symptom*’:ti,ab OR ‘mentally ill*’:ti,ab OR ‘mental illness*’:ti,ab OR ‘mental problem*’:ti,ab OR ‘mental disease*’:ti,ab OR ‘psychological disorder*’:ti,ab OR ‘psychological symptom*’:ti,ab OR ‘psychological diagnos*’:ti,ab OR ‘psychological illness*’:ti,ab OR ‘psychological disease*’:ti,ab OR ‘psychological problem*’:ti,ab OR ‘psychological patient*’:ti,ab OR ‘Psychiatric symptom*’:ti,ab OR ‘psychiatric disorder*’:ti,ab OR ‘psychiatric diagnos*’:ti,ab OR ‘psychiatric illness*’:ti,ab OR ‘psychiatric disease*’:ti,ab OR ‘psychiatric problem*’:ti,ab OR ‘psychiatric patients’:ti,ab OR ‘behavioural disorder*’:ti,ab OR ‘behavioral disorder*’:ti,ab OR ‘behaviour disorder*’:ti,ab OR ‘behavior disorder*’:ti,ab OR ‘psychological distress*’:ti,ab OR ‘Mental distress*’:ti,ab OR ‘Mentally distress*’:ti,ab OR ‘mental patient’/exp OR ‘Axis I disorder*’:ti,ab OR ‘Axis 1 disorder*’:ti,ab OR ‘affective disorder*’:ti,ab OR ‘anxiet*’:ti,ab OR ‘agoraphob*’:ti,ab OR ‘neurotic disorder*’:ti,ab OR ‘obsessive compulsive*’:ti,ab OR ‘ocd’:ti,ab OR ‘panic*’:ti,ab OR ‘phobi*’:ti,ab OR ‘gad’:ti,ab OR ‘bipolar*’:ti,ab OR ‘eating disorder*’:ti,ab OR ‘anorexi*’:ti,ab OR ‘Bulimi*’:ti,ab OR ‘Mood disorder*’:ti,ab OR ‘depress*’:ti,ab OR ‘dysthym*’:ti,ab OR ‘personality disorder*’:ti,ab OR ‘psychotic*’:ti,ab OR ‘psychosis*’:ti,ab OR ‘schizophren*’:ti,ab OR ‘psychosis’:ti,ab OR ‘somatoform disorder*’:ti,ab OR ‘trauma*’:ti,ab OR ‘posttraumatic stress’:ti,ab OR ‘post-traumatic stress’ OR ‘ptsd’:ti,ab

With filter for RCTs

Chapter 5 Appendix B

Definitions for the three main outcome categories: clinical, personal, and functional recovery

Recovery is a complex and multidimensional concept, and has been defined in various ways (Bellack, 2006; Jääskeläinen et al., 2013; Whitley & Drake, 2010). Three types of recovery can be differentiated, that are complementary aspects of recovery rather than mutual exclusive categories. Recovery can be seen as both outcome and process (Roosenschoon, Kamperman, Deen, Weeghel, & Mulder, 2019). For evaluating the effects of peer support interventions, we will examine the following three main types of outcomes:

1. Clinical or symptomatic recovery: the degree of psychiatric symptomatology (Slade et al., 2014; van Eck, Burger, Vellinga, Schirmbeck, & de Haan, 2018). This does not equate with symptomatic remission (the absence of a sustained reduction in symptoms).
2. Personal recovery, or sometimes referred to as subjective recovery (Mueser et al., 2006), highlights the personal nature of the recovery process; a term that originated among people with lived experience of mental illness (Deegan, 2002; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Mead & Copeland, 2000). It includes components such as spirituality, empowerment, actively accepting the illness, and also finding hope, re-establishing a positive identity, developing meaning in life, overcoming stigma, taking control of one's own life, and having supporting relationships (Cavelti, Kvrgic, Beck, Kossowsky, & Vauth, 2012). In a shorter definition, it concerns the extents of perceived recovery, sense of purpose, and personal agency (Mueser et al., 2006). To summarize the key elements of personal recovery, various authors use the acronym CHIME: Connectedness; Hope and Optimism about the future; Identity; Meaning in life; and Empowerment (Leamy et al., 2011). According to a recent systematic review and meta-analyses, "Difficulties and trauma" should be added, and the person's choice, risk taking, and coping with challenges should be emphasized in this framework (van Weeghel, van Zelst, Boertien, & Hasson-Ohayon, 2019).
3. Functional recovery or objective recovery (Mueser et al., 2006): the degree of vocational and social functioning, such as acting according to age-appropriate role expectations, the performance of daily living tasks without supervision, engagement in social interactions (Robinson, Woerner, McMeniman, Mendelowitz, & Bilder, 2004), and the degree of independence with regard to housing (Harvey & Bellack, 2009; Whitley & Drake, 2010). Functional recovery thus concerns functional outcomes rather than functional capacity (Carrión et al., 2013; Patterson & Mausbach, 2010). Some studies interpret functional recovery with functional remission (Harvey & Bellack, 2009), others consider it part of clinical recovery (Liberman & Kopelowicz, 2002; Slade et al., 2012)

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Chapter 5 Appendix C

Details for data extraction and calculating Risk of Bias scores

Decision tool for data extraction of control conditions:
CAU control groups were prioritized for extraction over WL control groups when multiple control groups were available.

Decision tool for data extraction of multiple available instruments within one outcome category:
For (1) clinical recovery we chose (1a) a specific-disorder instrument over a transdiagnostic instrument if all participants were recruited based on one specific disorder. We chose a transdiagnostic instrument if multiple disorders were included. Furthermore, we chose (1b) a clinician-rated instrument over a self-reported measure. For (2) personal and functional recovery we chose instruments regarding global functioning in these domains over a more specific instrument. For example, we used data for personal and functional recovery for a more general instrument, the Recovery Assessment Schedule (RAS) over instruments for empowerment specifically (e.g., Empowerment Scale), and we extracted data for Quality of Life (e.g., Lehman's Quality of Life) rather than data of measurements on -often considered- a subcategory of Quality of Life, social support.

Details for calculating Risk of Bias score for domain 4
Trials that used both self-report measures and (blinded) clinician rated instruments were rated at low risk and some concerns for bias for domain 4 (inappropriate measurement of the outcome) if the type of measurement instrument differed per outcome category. For example, when authors used a self-report measure for clinical recovery and a blinded-clinician rated instrument for personal recovery, domain 4 was rated at some concerns for bias for the clinical recovery outcome category and at low risk for bias for the outcome category personal recovery.

Details for calculating an overall Risk of Bias score:
Overall high risk of bias was determined when any of the domains had a high risk score, or if 4 domains were rated as having “some concerns”. An overall low risk score was given when 4 domains were rated as low risk. An overall rating of some concerns was given in the remaining situations.

Details for data extraction per outcome category:
For clinical recovery instruments, we extracted means (*SD*) values of baseline, the primary end point and longest follow-up measurement for both the intervention and the control groups including sample sizes. For personal and functional recovery instruments, we extracted posttest and follow-up data when available for both intervention and the control groups.

Chapter 5 Appendix D

Selected Characteristics of Included Studies

Author and publication year	Country	Population and Diagnoses	Sub-group	% Female	Age (M)	Recruitment [a]	Clinical diagnosis or cut-off	Sample size at post for clinical outcome: intervention/ control
Boevink 2016	NL	SMI: 40.5% Non-affective psychotic disorder; 15.9% Affective disorder; 15% Personality disorder; 25% Other.	NA	47.4	43.9	Clinical (Inpatients + Outpatients)	Diagnosis	65/73
Castelein 2008	NL	SMI: Psychosis (Schizophrenia 74.5%; Other 25.5%).	NA	34.5	38.55	Clinical (Not specified)	Diagnosis	56/50
Cook 2012a	USA	SMI: Bipolar disorder 38%; Depressive disorder 25%; other 13%; Schizophrenia 12%; Schizoaffective disorder 10%.	NA	66	45.8	Mixed	Diagnosis	224/234
Cook 2012b	USA	SMI: Bipolar disorder 39.5%; Depressive disorder 18%; Schizophrenia 15.4%, Schizo-affective disorder 5.4%; Other 8.6%.	NA	55.6	42.8	Mixed	Diagnosis	170/172
Corrigan 2017	USA	SMI: Major Depressive Disorder 49%; Bipolar disorder 17%; Anxiety disorder 12% Schizophrenia 10%.	Yes: Homeless African Americans	39.0	52.88	Mixed	Diagnosis	34/33
Corrigan 2018	USA	SMI: Major Depressive Disorder 68%; Anxiety 21%; Bipolar disorder 7%; Other.	Yes: Latinos	58.5	45.65	Clinical (Not specified)	Diagnosis	55/55
Craig 2004	UK	SMI: Paranoid schizophrenia 87%; drug/alcohol abuse 29%.	Yes: Long-term unemployed individuals	33.3	37.6	Clinical (Outpatients)	Diagnosis	24/21

Intervention (name or reference in paper; structure; delivery; format; duration)	Control condi-tion	Outcomes	Assessments	Post (months)	Long-term Follow-up (months)	Overall Risk of Bias rating
Peer-led structured face-to-face group intervention; 12 months (2-hour sessions, biweekly)	WL	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Personal recovery (empowerment) 3) Functional recovery (Quality of Life)	1) Community Assessment of Psychich Experiences (CAPE) 2) Boston Empowerment Scale 3) Lancashire Quality of Life Profile (LQOLP)	12	NA	High Risk
Peer-led unstructured face-to-face group intervention; 8 months (1.5-hour sessions, biweekly)	WL	1) Personal recovery (empowerment) 2) Functional recovery (Quality of Life)	1) Mental Health Confidence Scale (MHSC) 2) The World Health Organisation Quality of Life (WHOQOL)	8	NA	Some concerns
Wellness Recovery Action Plan (WRAP): Peer-led structured face-to-face group intervention; 2 months (2.5-hour sessions, weekly)	WL	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Personal recovery (overall personal recovery) 3) Functional recovery (Quality of Life)	1) Brief Symptom Inventory (BSI) 2) Recovery Assessment Scale (RAS) 3) The World Health Organisation Quality of Life (WHOQOL)	2	8	High Risk
Building Recovery of Individual Dreams and Goals through Education and Support (BRIDGES): Peer-led structured face-to-face group intervention; 2 months (2.5-hour sessions, weekly)	WL	1) Personal recovery (overall personal recovery)	1) Recovery Assessment Scale (RAS)	3.5	9	High Risk
Peer Navigator Program (PNP): Peer-led unstructured face-to-face individual intervention; duration not specified (weekly with flexible frequency)	CAU	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Personal recovery (overall personal recovery) 3) Functional recovery (Quality of Life)	1) Texas Christian University Health Form (TCU HF) 2) Recovery Assessment Scale (RAS) 3) Short Form 36 Health Survey (SF-36)	8	12	Some concerns
Peer Navigator Program (PNP): Peer-led unstructured face-to-face individual intervention; 6 months (weekly with flexible frequency)	CAU	1) Personal recovery (overall personal recovery) 2) Functional recovery (Quality of Life)	1) Recovery Assessment Scale (RAS) 2) Quality of Life Scale (QLS)	8	12	High Risk
Consumer-employee assistant health case management: Peer-led unstructured face-to-face individual intervention; duration not specified	CAU	1) Functional recovery (functioning)	1) Life Skill Profile (LSP)	12	NA	Some concerns

Author and publication year	Country	Population and Diagnoses	Sub-group	% Female	Age (*M*)	Recruit-ment [a]	Clinical diagnosis or cut-off	Sample size at post for clinical outcome: intervention/ control
Davidson 2004	USA	SMI: Psychotic disorder 50%; Affective disorder 34%; Anxiety disorder 2%; Other Axis-I disorder 1%; Unknown 12%.	NA	43	42	Clinical (Outpatients)	Diagnosis	95/70
Dennis 2003	Canada	Depression: Postpartum depression	Yes: Perinatal depression	100	NA (76.5% between 25-34 years)	Other	Cut-off	20/22
Dennis 2009	Canada	Depression: Postpartum depression	Yes: Perinatal depression	100	NA (78% between 20-34 years)	Other	Cut-off	297/315
Field 2013 *Not included in MA*	USA	Depression: Prenatal depression	Yes: Perinatal depression	100	24.9	Other	Diagnosis	22/22
Gjerdingen 2013	USA	Depression: Postpartum depression	Yes: Perinatal depression	100	29.7	Other	Cut-off	11/14
Griffiths 2012	Australia	Depression: Diagnoses not specified	NA	61	44.6	General population	Cut-off	52/71
Johnson 2018	UK	SMI (PS/CTR): Depression 23/25%; Schizophrenia or Schizoaffective disorder 13/15%; Bipolar 13/12%; Borderline 8/10%; Other Psychosis 6/4%.	NA	60	40	Inpatients	Diagnosis	218/216

Intervention (name or reference in paper; structure; delivery; format; duration)	Control condition	Outcomes	Assessments	Post (months)	Long-term Follow-up (months)	Overall Risk of Bias rating
The Partnership Project: Peer-led unstructured face-to-face individual intervention; 9 months (2 to 4-hour session, weekly)	CAU	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Personal recovery (overall personal recovery) 3) Functional recovery (functioning)	1) Brief Psychiatric Rating Scale (BPRS) 2) Wellbeing Scale (WBS) 3) Global Assessment of Functioning (GAF)	9	NA	High Risk
Mother-to-mother telephone based peer support: Peer-led unstructured telephone individual intervention; duration not specified	CAU	1) Clinical recovery (depression) 2) Functional recovery (Loneliness)	1) Edinburgh Postnatal Depression Scale (EPSD) 2) University of California Los Angeles Loneliness Scale (UCLA LS)	2	NA	Low Risk
Mother-to-mother telephone based peer support: Peer-led unstructured telephone individual intervention; 3 months (flexible frequency)	CAU	1) Clinical recovery (depression) 2) Functional recovery (Loneliness)	1) Edinburgh Postnatal Depression Scale (EPSD) 2) University of California Los Angeles Loneliness Scale (UCLA LS)	3	6	Some concerns
Peer support group: Peer-led unstructured face-to-face group intervention: 3 months (sessions weekly)	Clinician-led control group	1) Clinical recovery (depression)	1) Center for Epidemiologic Studies Depression (CES-D)	3	NA	High Risk
Peer telephone support: Peer-led unstructured telephone individual intervention; 3 months (flexible frequency)	CAU	1) Clinical recovery (depression) 2) Functional recovery (Quality of Life)	1) Center for Epidemiologic Studies Depression (CES-D) 2) EuroQoL 5D (EQ-5D)	3	6	High Risk
Wellbeing board, a moderated internet support group: Peer-led unstructured internet group intervention; 3 months (minimum of 2 logins weekly)	Attention control	1) Clinical recovery (depression) 2) Personal recovery (empowerment) 3) Functional recovery (Quality of Life)	1) Center for Epidemiologic Studies Depression (CES-D) 2) Empowerment Scale (subscale power-powerlessness) 3) EUROHIS QOL 8-item index (EUROHIS QOL)	3	6	High Risk
Peer-supported self-management intervention, based on a recovery workbook: Peer-led structured face-to-face individual intervention; 4 months (1-hour sessions, weekly)	CAU	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Personal recovery (overall personal recovery) 3) Functional recovery (loneliness)	1) Brief Psychiatric Rating Scale (BPRS) 2) Questionnaire about the Process of Recovery (QPR) 3) University of California Los Angeles Loneliness Scale (UCLA LS)	4	18	High Risk

Author and publication year	Country	Population and Diagnoses	Subgroup	% Female	Age (M)	Recruitment [a]	Clinical diagnosis or cut-off	Sample size at post for clinical outcome: intervention/ control
Kaplan 2011	USA	SMI: Schizophrenia Spectrum 22.41%; Affective disorder 77.59%.	NA	65.67	47	Mixed	Diagnosis	99/100
Letourneau 2011	Canada	Depression: Postpartum depression	Yes: Perinatal	100	Majority 26-35 years.	Mixed	Cut-off	23/28
Ludman 2007	USA	Depression: Dysthymia 79%; Major depressive disorder 55%; Panic disorder 33%; Generalised anxiety disorder 28%; Borderline personality disorder 13%.	NA	72	50.2	Clinical (Inpatients+ Outpatients)	Diagnosis	20/21
Mahlke 2017	Germany	SMI: Unipolar depression 25%; Personality disorder 23%; Schizophrenia 22%; Bipolar disorder 15%; Schizoaffective disorder 6%; Other/ NA both 5%.	NA	57	41.48	Clinical (Inpatients+ Outpatients)	Diagnosis	61/42
Matthews 2018 *Not included in MA*	USA	Hoarding disorder	Yes: Depression (Anxiety)	74.5	58.95	Mixed	Cut-off	163/160
O'Connell 2018	USA	SMI (PSI/CTR): Psychotic disorder 72/78%; Mood disorder 28/22%.	NA	50	40.1	Clinical (Inpatients)	Diagnosis	34/29

Intervention (name or reference in paper; structure; delivery; format; duration)	Control condi-tion	Outcomes	Assessments	Post (months)	Long-term Follow-up (months)	Overall Risk of Bias rating
An unmoderated internet support group: Peer-led unstructured online group intervention; duration not specified (flexible frequency)	WL	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Personal recovery (overall personal recovery) 3) Functional recovery (Quality of Life)	1) Hopkins Symptoms Checklist-58 (HSCL-58) 2) Recovery Assessment Scale (RAS) 3) Quality of Life Lehman (QoL Lehman)	4	12	Some concerns
Home-based peer support intervention: Peer-led structured face-to-face and telephone individual intervention; 3 months (flexible frequency)	WL	1) Clinical recovery (depression) 2) Functional recovery (functioning)	1) Edinburgh Postnatal Depression Scale (EPSD) 2) Social Provision Scale (SPS)	3	NA	High Risk
Chronic disease self-management program: Peer-led structured face-to-face group intervention; 1.5 month (sessions weekly)	Other inactive control + Clinician-led control group	1) Clinical recovery (overall [transdiagnostic] clinical symptoms)	1) Structured Clinical Interview for DSM-IV (SCID)	12	NA	High Risk
Peer-led unstructured face-to-face individual intervention; 6 months (flexible, in principle 1-hour sessions, biweekly)	CAU	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Personal recovery (Empowerment) 3) Functional recovery (Quality of Life)	1) Clinical Global Impression Scale (CGI) 2) General Self-efficacy Scale (GSE) 3) EuroQoL 5D (EQ-5D)	6	12	High Risk
Group Peer Facilitated Therapy (G-PFT): Peer-led unstructured face-to-face group + telephone individual intervention; 5 months (sessions approximately weekly)	Clinician-led Cognitive Behavioural Therapy	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Functional recovery (functioning)	1) Saving Inventory-Revised (SI-R) 2) Activities of Daily Living Scale in Hoarding Disorder (ADL-H).	5	8	High Risk
Recovery mentor: Peer-led unstructured face-to-face and/or telephone individual intervention; up to 9 months (flexible frequency, recommended weekly sessions)	CAU	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Functional recovery (Quality of Life)	1) Brief Psychiatric Rating Scale (BPRS) 2) Short Form 36 Health Survey, 2 items on social functioning (SF-36)	9	NA	High Risk

Author and publication year	**Country**	**Population and Diagnoses**	**Sub-group**	**% Female**	**Age (*M*)**	**Recruit-ment** [a]	**Clinical diagnosis or cut-off**	**Sample size at post for clini-cal outcome: intervention/ control**
Pfeiffer 2019	USA	SMI: Unipolar mood disorder 58%; Bipolar mood disorder 12%; Schizophrenia 4%; Anxiety disorder 4%; Substance use disorder 6%; Personality disorder 10%; Other 5%.	NA	53	34	Clinical (Inpatients)	Other: Medical record documentation or suicidal ideation om Beck Scale for Suicidal Ideation ≥ 5.	24/31
Ranzenhofer 2020	USA	Other: Eating disorders: Anorexia Nervosa 65%; Atypical Anorexia Nervosa 10%; Boulimia Nervosa 20%; Binge Eating Disorder 5%.	NA	100	27.48	Clinical (Inpatients + Outpatients)	Diagnosis	18/20
Rivera 2007	USA	SMI: Schizophrenia 29%; Schizoaffective disorder 20%; Bipolar disorder 26%; Depressive disorder 22%.	NA	49	38.3	Clinical (Inpatients)	Diagnosis	65/65
Rogers 2016	USA	SMI: Diagnoses not specified	Yes: Civil Commit-ted	55.75	39.67	Clinical (Inpatients)	Other: Adjudicated by the state court	25/50 (high level of engagement) 28/50 (low level of engagement)
Rüsch 2014	Switzer-land	SMI: Depressive disorder 56%; Schizophrenia spectrum disorder 32%; Bipolar disorder 32% (including overlap).	NA	59	41.95	Mixed	Diagnosis	39/47
Russinova 2014	USA	SMI: Schizophrenia Spectrum Disorder 34%; Bipolar disorder 33%; Depressive disorder 26%; Other 7%.	NA	68	Most participant were older than 40 (N = 556, 68%)	Clinical (Outpatients)	Diagnosis	40/42

Intervention (name or reference in paper; structure; delivery; format; duration)	**Control condi-tion**	**Outcomes**	**Assessments**	**Post (months)**	**Long-term Follow-up (months)**	**Overall Risk of Bias rating**
Peers for Valued Living (PREVAIL): Peer-led structured mixed (primarily face-to-face with supporting text messages, mail, telephone) individual intervention; 3 months (flexible frequency, encouraged (bi)weekly)	CAU	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Personal recovery (Hope) 3) Functional recovery (functioning)	1) Beck Scale for Suicide Ideation (BSSI) 2) Hope Scale (HS) 3) NIH Toolbox Adult Social Relationship Scales (NIH Toolbox)	3	6	High Risk
Peer mentorship: Peer-led mixed (face-to-face or online) individual intervention (structure not specified); 6 months (1 hour sessions, weekly)	WL	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Functional recovery (Quality of Life)	1) Eating Pathology Symptoms Inventory (EPSI) 2) Eating Disorder Quality of Life (ED QOL)	6	6	Low risk
Consumer assisted case management: Peer-led unstructured blended individual and group face-to-face intervention; 6 months (flexible frequency)	CAU	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Functional recovery (Quality of Life)	1) Brief Symptom Inventory (BSI) 2) Quality of Life Lehman (QoL Lehman)	6	12	High risk
Peer support specialists: Peer-led unstructured face-to-face individual intervention; 6 months (sessions weekly)	CAU	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Personal recovery (overall personal recovery) 3) Functional recovery (Quality of Life)	1) Behavior And Symptom Identification Scale 24 (BASIS-24) 2) Recovery Assessment Scale (RAS) 3) Quality of Life Lehman (QoL Lehman)	6	6	High risk
Coming Out Proud: Peer-led structured face-to-face group intervention; 0.75 months (2-hours sessions, weekly)	CAU	1) Personal recovery (Empowerment)	1) Empowerment Scale (ES)	0.75	NA	High risk
Antistigma photovoice program: Peer-led structured face-to-face group intervention; 3 months (1.5 hours-sessions, weekly)	WL	1) Clinical recovery (depression) 2) Personal recovery (overall personal recovery)	1) Center for Epidemiologic Studies Depression (CES-D) 2) Personal Growth and Recovery Scale (PGRS)	5.3	NA	Some concerns

Author and publication year	**Country**	**Population and Diagnoses**	**Sub-group**	**% Female**	**Age (*M*)**	**Recruit-ment** [a]	**Clinical diagnosis or cut-off**	**Sample size at post for clini-cal outcome: intervention/ control**
Salzer 2016	USA	SMI: Schizophrenia; Bipolar disorder; Major Depression (% NA).	NA	46.5	48.7	Clinical (Outpatients)	Diagnosis	50/49
Shorey 2019	Singa-pore	Depression: Postnatal depression	Yes: Perinatal depres-sion	100	32.1	Clinical (Other)	Cutt-off	56/58
Solomon 1995	USA	SMI: Schizophrenia 86%; Major affective disorder 13%.	NA	48	37.09	Clinical (Outpatients)	Diagnosis	48/48
Van Gestel-Timmermans 2012	NL	SMI: Psychosis 33.46%; Affective disorder 36.5%; Anxiety disorder 22.47%; Personality disorder 32.02%.	NA	66.02	43.49	Mixed	Diagnosis	136/117

Note. Abbreviations: CAU = care as usual; CTRL = Control; MA = Meta-Analysis; NA = Not Applicable; PSI = Peer Support Intervention; SMI = Serious Mental Illness; WL = Waiting List.

[a] Studies with mixed recruitment included both a clinical group (inpatients and/or outpatients) and individuals recruited in the general population.

Intervention (name or reference in paper; structure; delivery; format; duration)	Control condition	Outcomes	Assessments	Post (months)	Long-term Follow-up (months)	Overall Risk of Bias rating
Peer-delivered Core Centre Independent Living: Peer-led structured face-to-face and telephone individual intervention; 6 months (flexible frequency)	CAU	1) Personal recovery (overall personal recovery) 2) Functional recovery (Quality of Life)	1) Recovery Assessment Scale (RAS) 2) Quality of Life Lehman (QoL Lehman)	6	12	High risk
Technology-based peer-support intervention program: Peer-led unstructured mixed (email, telephone, text messages) individual intervention; 1 month (flexible frequency, on average weekly sessions)	CAU	1) Clinical recovery (depression) 2) Functional recovery (functioning)	1) Edinburgh Postnatal Depression Scale (EPSD) 2) Perceived Social Support for Parenting (PSSP)	1	NA	Low risk
Consumer case management: Peer-led unstructured face-to-face individual intervention; 12 months (flexible frequency)	Active control	1) Clinical recovery (overall [transdiagnostic] clinical symptoms) 2) Functional recovery (Quality of Life)	1) Brief Psychiatric Rating Scale (BPRS) 2) Quality of Life Lehman (QoL Lehman)	12	24	High risk
Recovery is up to you: Peer-led structured face-to-face group intervention; 3 months (2-hours sessions, weekly)	WL	1) Personal recovery (Empowerment) 2) Functional recovery (Quality of Life)	1) Netherlands Empowerment List (NEL) 2) Manchester Short Assessment of Quality of Life	3	6	High risk

Chapter 5 Appendix E

References, list of included studies in the systematic review and meta-analyses

List of studies included in the meta-analysis (n = 28):

1. Boevink, W., Kroon, H., van Vugt, M., Delespaul, P., & van Os, J. (2016). A user-developed, user run recovery programme for people with severe mental illness: A randomised control trial. Psychosis, 8, 287-300.
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[a] *The study from Ludman et al. (2007) is included in the meta-analysis as well as narratively described since the peer support intervention is compared to both an inactive control condition and a clinician-led control condition.*

Chapter 5 Appendix F

Narrative description of three RCTs with a clinician-led comparator

Only three papers (Field et al., 2013; Ludman et al., 2007; Mathews et al., 2018) that met our inclusion criteria compared a Peer Support Intervention (PSI) to a clinician-led control condition and were, due to this limited number, not included in the meta-analysis. The three studies were conducted in the USA, examining PSIs with face-to-face delivery and group format. The studies included heterogeneous samples (see Appendix D).

Field and colleagues (2013) compared a 3-month unstructured PSI with an Interpersonal Psychotherapy (IPT) Group in 44 patients with a clinical diagnosis of prenatal depression, recruited from 2 medical centres. The study was rated as high risk of bias. A significant decrease of depression symptoms (measured by the Center for Epidemiologic Studies Depression [CES-D]) was reported in both the peer support condition and the psychotherapy control condition. The decrease was greater in the peer support group, though results should be interpreted with caution due to low power.

Ludman and colleagues (2007) compared an 1.5-month structured PSI with a professionally-led psychotherapy group with principles of Cognitive Behavioral Therapy (CBT) in 52 patients scoring above a cut-off level on a depression measure, which were recruited in a clinical setting. The risk of bias (RoB) for this study was rated as high risk. Although differences were not significant, 24% was diagnosed with a depressive disorder in the peer support condition at the end of treatment compared to 20% in the clinician-led control condition. Also, the Hopkins Symptom Checklist (HSCL) depression scores did not differ significantly between groups. The sample was too small to reliably detect differences in clinical outcomes.

The non-inferiority trial of Mathews and colleagues (2018) compared a 5-month unstructured PSI with a clinician-led group CBT in 323 individuals with hoarding disorder scoring above a cut-off level on a hoarding disorder symptom measure. Both inpatients, outpatients, and individuals in the general community were recruited for participation. The risk of bias for this study was rated as high risk. Mathews et al. (2018) reported a reduction of symptoms (assessed by the Saving Inventory-Revised [SI-R]) with an effect size of 1.20 for the peer-led group, and 1.21 for the clinician-led control condition, with no significant differences between them.

Overall, the quality of studies was low, with an overall score of high risk (see Figure G2 in Appendix G, and the table in Appendix H). Therefore, results should be considered with caution. Collectively, the effects of the interventions were primarily measured in terms of clinical recovery, with 2 trials (Field et al., 2013; Mathews et al., 2018) indicating that peer-led groups were as effective as psychologist-led groups for reducing symptom severity.

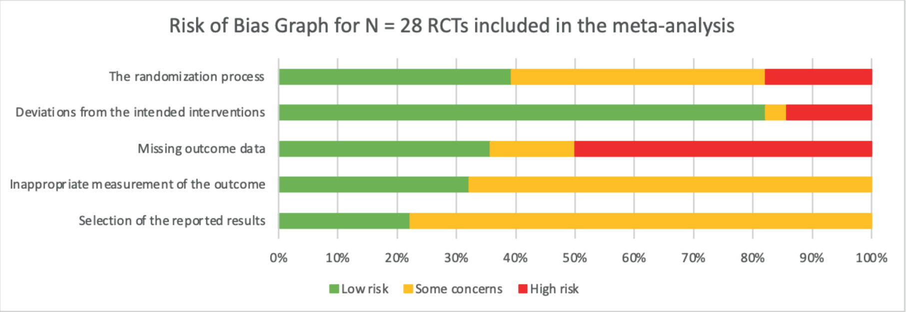
References of RCTs with a clinician-led comparator

1. Field T, Diego M, Delgado J, Medina L. Peer support and interpersonal psychotherapy groups experienced decreased prenatal depression, anxiety and cortisol. *Early Hum Dev*. 2013;89(9):621-624.
2. Ludman EJ, Simon GE, Grothaus LC, Luce C, Markley DK, Schaefer J. A pilot study of telephone care management and structured disease self-management groups for chronic depression. *Psychiatr Serv*. 2007;58(8):1065-1072.
3. Mathews CA, Mackin RS, Chou CY, et al. Randomised clinical trial of community-based peer-led and psychologist-led group treatment for hoarding disorder. *BJPsych Open*. 2018;4(4):285-293.

Chapter 5 Appendix G

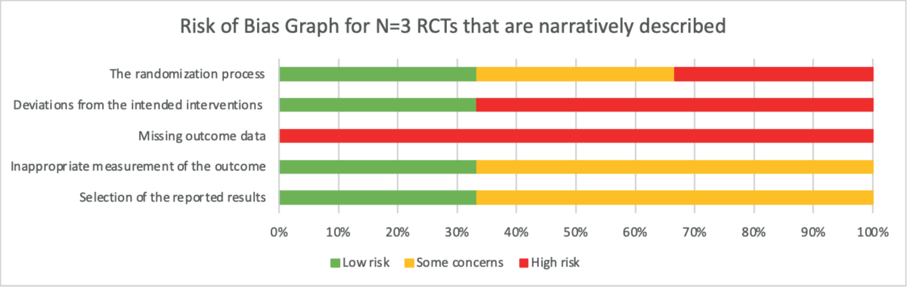
Risk of Bias Graphs

Figure G1



Risk of Bias Graphs: Review Authors' Judgments About Each Risk of Bias Item Presented as Percentages Across Included Studies in the Meta-Analysis (n = 28)

Figure G2



Risk of Bias Graph: Review Authors' Judgments About Each Risk of Bias Item Presented as Percentages Across Included Studies narratively described (n = 3)

Chapter 5 Appendix H

Risk of Bias rating per study: subdomains and overall rating using the Cochrane Collaboration Risk of Bias (RoB) tool 2.0

Author, year of publication	**Domain 1** ***The randomization process***	**Domain 2** ***Deviations from the intended interventions***	**Domain 3** ***Missing outcome data***	**Domain 4** [a] ***Inappropriate measurement of the outcome***	**Domain 5** ***Selection of the reported results***	**Overall RoB rating**
Studies included in the meta-analysis (with CAU, WL or Other inactive control condition as comparator)						
Boevink, 2016	Some concerns	Low risk	Some concerns	Some concerns	Some concerns	High risk
Castelein, 2008	Low risk	Low risk	Low risk	Some concerns	Some concerns	Some concerns
Cook, 2012a	Low risk	Low risk	High risk	Low risk	Some concerns	High risk
Cook, 2012b	Low risk	Low risk	High risk	Low risk	Some concerns	High risk
Corrigan, 2017	Some concerns	Low risk	Low risk	Some concerns	Some concerns	Some concerns
Corrigan, 2018	High risk	High risk	High risk	Some concerns	Some concerns	High risk
Craig, 2004	Some concerns	Low risk	Low risk	Low risk & Some concerns	Some concerns	Some concerns
Davidson, 2004	Some concerns	High risk	High risk	Some concerns	Some concerns	High risk
Dennis, 2003	Low risk	Low risk	Low risk	Low risk	Some concerns	Low risk
Dennis, 2009	Low risk	Low risk	Some concerns	Low risk	Some concerns	Some concerns
Gjerdingen, 2013	High risk	Low risk	Low risk	Some concerns	Some concerns	High risk
Griffiths, 2012	Low risk	Low risk	High risk	Some concerns	Low risk	High risk
Johnson, 2018	High risk	Low risk	Some concerns	Low risk & Some concerns	Low risk	High risk
Kaplan, 2011	Some concerns	Low risk	Low risk	Some concerns	Some concerns	Some concerns
Letourneau, 2011	Some concerns	Low risk	High risk	Low risk	Some concerns	High risk
Ludman, 2007	Some concerns	Low risk	High risk	Low risk	Some concerns	High risk
Mahlke, 2017	Low risk	Low risk	High risk	Low risk & Some concerns	Some concerns	High risk

Author, year of publication	**Domain 1** ***The randomization process***	**Domain 2** ***Deviations from the intended interventions***	**Domain 3** ***Missing outcome data***	**Domain 4** [a] ***Inappropriate measurement of the outcome***	**Domain 5** ***Selection of the reported results***	**Overall RoB rating**
Studies included in the meta-analysis (with CAU, WL or Other inactive control condition as comparator)						
O'Connell, 2018	Some concerns	Low risk	High risk	Low risk	Some concerns	High risk
Pfeiffer, 2019	Some concerns	Low risk	High risk	Some concerns	Some concerns	High risk
Ranzenhofer, 2020	Low risk	Low risk	Low risk	Some concerns	Low risk	Low risk
Rivera, 2007	Some concerns	High risk	Some concerns	Low risk	Some concerns	High risk
Rogers, 2016	High risk	High risk	High risk	Some concerns	Some concerns	High risk
Rüsch, 2014	Low risk	Low risk	High risk	Some concerns	Some concerns	High risk
Russinova, 2014	Some concerns	Low risk	Low risk	Some concerns	Some concerns	Some concerns
Salzer, 2016	Some concerns	Low risk	High risk	Some concerns	Some concerns	High risk
Shorey, 2019	Low risk	Low risk	Low risk	Some concerns	Low risk	Low risk
Solomon, 1995	High risk	Some concerns	Low risk	Low risk	Some concerns	High risk
van Gestel-Timmermans, 2012	Low risk	Low risk	High risk	Some concerns	Some concerns	High risk
		Studies narratively described in the systematic review (with clinician-led control condition as comparator)				
Field, 2013	High risk	High risk	High risk	Some concerns	Some concerns	High risk
Ludman, 2007	Some concerns	Low risk	High risk	Low risk	Some concerns	High risk
Mathews, 2018	Low risk	High risk	High risk	Some concerns	Low risk	High risk

Abbreviations: CAU = Care-as-usual; RoB = Risk of Bias; WL = Waiting List.

[a] Three trials were rated at both low risk and some concerns for bias in domain 4 due to the use of other types of measurement instruments per outcome category (e.g., using self-report measures for clinical recovery, and blinded-clinician rated instruments for personal recovery).

Chapter 5 Appendix I

Subgroup analyses on moderators per outcome category: Clinical, Personal, and Functional Recovery Outcomes, Hedges *g*

Moderator	**Clinical Recovery**			**Personal Recovery**			**Functional Recovery**		
	No. of studies	***g* [95% CI]**	***p***	**No. of studies**	***g* [95% CI]**	***p***	**No. of studies**	***g* [95% CI]**	***p***
Type of disorder									
Individuals with depressive symptoms [a]	7	0.19 [-0.12, 0.51]	0.95	2	0.18 [-0.02, 0.37]	0.83	6	0.02 [-0.25, 0.29]	0.65
Serious Mental Illness (SMI) [b]	14	0.18 [0.11, 0.25]		17	0.15 [0.03, 0.27]		18	0.08 [-0.02, 0.19]	
Inclusion [c]									
Cut-off	6	0.18 [-0.18, 0.55]	0.93	NA	NA		6	0.02 [-0.25, 0.29]	0.41
Diagnosis	13	0.20 [0.12, 0.27]		NA	NA		15	0.14 [0.02, 0.26]	
Recruitment									
Clinical	13	0.17 [0.08, 0.26]	0.64	11	0.11 [-0.07, 0.29]	0.25	14	0.07 [-0.09, 0.22]	0.76
Other/mixed [d]	9	0.21 [0.08, 0.34]		8	0.22 [0.15, 0.29]		11	0.09 [0.01, 0.19]	
Delivery [e]									
In distance	5	0.22 [0.10, 0.34]	0.74	3	0.16 [0.06, 0.26]	0.57	5	0.14 [0.01, 0.26]	0.45
In person	13	0.16 [0.09, 0.24]		15	0.12 [0.04, 0.21]		15	0.04 [-0.04, 0.12]	
Mixed	4	0.20 [-0.31, 0.70]		NA	NA		5	0.12 [-0.34, 0.58]	
Format									
Group	6	0.16 [0.07, 0.25]	0.69	9	0.20 [0.10, 0.29]	0.54	6	0.12 [0.08, 0.17]	0.44
Individual	15	0.19 [0.09, 0.30]		10	0.13 [-0.07, 0.33]		18	0.06 [-0.08, 0.21]	
Comparator									
CAU	12	0.23 [0.15, 0.31]	0.38	10	0.18 [-0.01, 0.36]	0.33	15	0.05 [-0.11, 0.20]	0.81
Other active or inactive control	4	0.14 [-0.06, 0.34]		2	-0.06 [-0.38, 0.26]		3	0.17 [-0.19, 0.46]	

	Clinical Recovery			Personal Recovery			Functional Recovery		
Moderator	**No. of studies**	***g* [95% CI]**	***p***	**No. of studies**	***g* [95% CI]**	***p***	**No. of studies**	***g* [95% CI]**	***p***
WL	6	0.09 [-0.14, 0.31]		7	0.20 [0.09, 0.31]		7	0.10 [0.00, 0.21]	
Specific subgroup [f]									
Yes	8	0.17 [-0.09, 0.42]	0.87	6	0.09 [-0.05, 0.23]	0.44	10	-0.01 [-0.18, 0.15]	0.18
No	14	0.19 [0.12, 0.26]		13	0.17 [0.03, 0.31]		15	0.12 [0.01, 0.24]	
Perinatal depression									
Yes	5	0.19 [-0.28, 0.66]	0.99	NA	NA		20	0.10 [-0.01, 0.20]	0.46
No	17	0.19 [0.12, 0.25]		NA	NA		5	-0.04 [-0.39, 0.31]	
Structured vs unstructured [g]									
Structured	7	0.11 [-0.02, 0.25]	0.13	9	0.23 [0.05, 0.42]	0.12	7	0.10 [-0.15, 0.36]	0.80
Unstructured	14	0.24 [0.15, 0.32]		10	0.06 [-0.04, 0.16]		17	0.05 [-0.03, 0.17]	

Note. Abbreviations: CI = Confidence Interval; NA = Not Applicable

[a] Participants scoring above a cut-off level on a depression scale for k = 6 (of which k = 5 are on perinatal depression); Participants with a clinical diagnosis of depression for k = 1.

[b] A heterogeneous sample of clinically diagnosed mental health disorders, including diagnoses of depressive disorders for k=17, k=3 did not specify including depression.

[c] Participants were included based on (1) scoring above a cut-off level on a validated measurement scale or (2) clinical diagnosis or documentation.

[d] Studies with mixed recruitment included both a clinical group (inpatients and/or outpatients) and individuals recruited in the general population.

[e] *In distance* refers to telephone and internet interventions; *In person* refers to face-to-face interventions; *Mixed* refers to a combination of different formats.

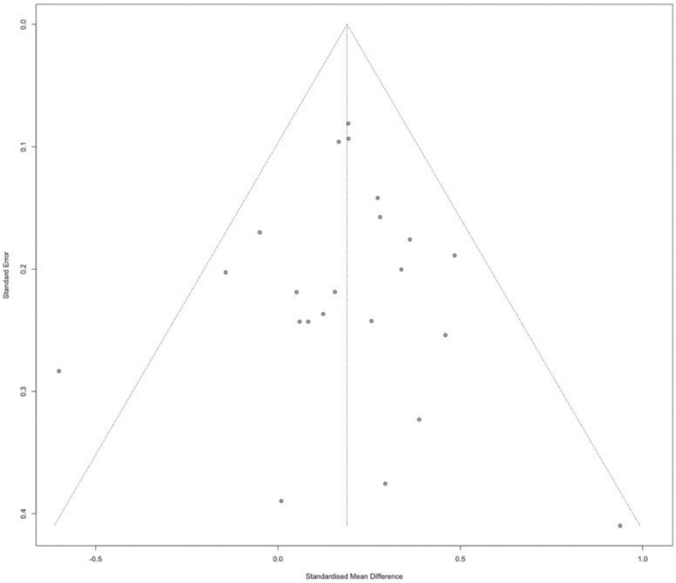
[f] Whether the population is a specific subgroup of the general community (e.g., cultural background such as Latino's) or aa patient subgroup (e.g., perinatal depression).

[g] Whether the peer support intervention was structured (peer leaders followed a manual or pre-determined topics) or not (no manual, meetings based on mutual support solely).

Chapter 5 Appendix J

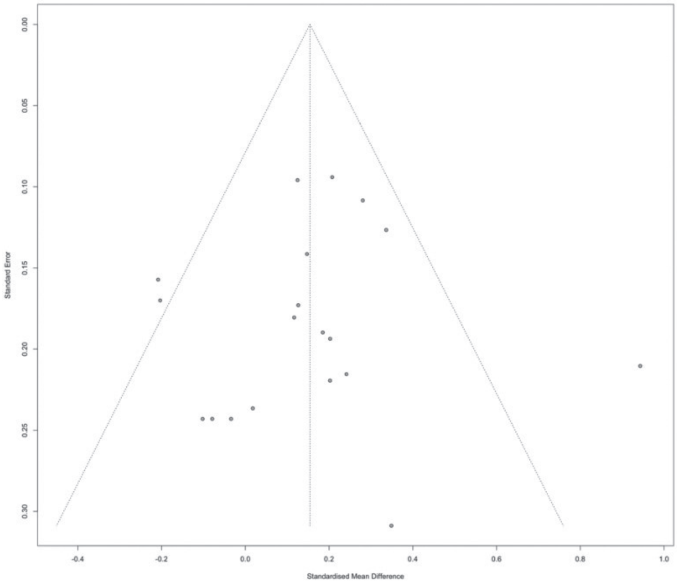
Funnel Plots

Figure J1. *Funnel plot for clinical recovery*



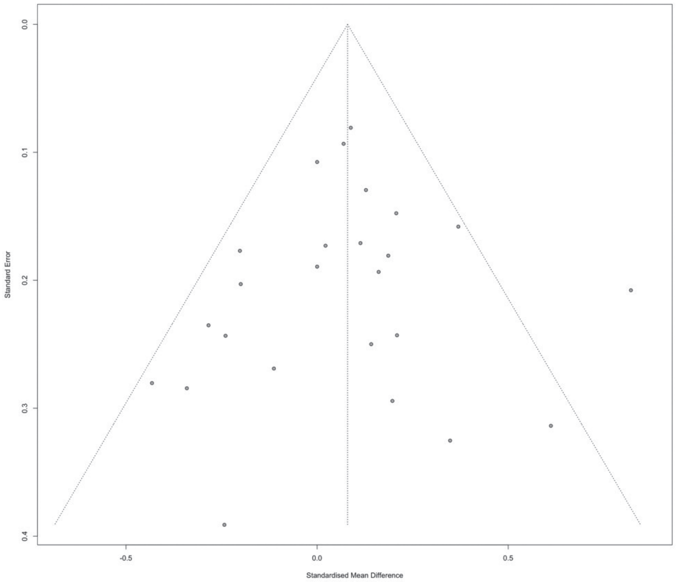
Note. For clinical recovery, we found no indication that publication bias affected the results. Egger's test of the asymmetry of the funnel plot was nonsignificant ($p = 0.99$). Adjusting for publication bias through the Duval and Tweedie's trim and fill procedure showed an effect size of $g = 0.18$, 95% CI [0.10, 0.27], with one imputed study.

Figure J2. *Funnel plot for personal recovery*



Note. For personal recovery we found no indication for publication bias, with Egger's test nonsignificant (p = 0.66). Adjusting for publication bias through the Duval and Tweedie's trim and fill procedure resulted in effect size g = 0.23, 95% CI [0.12, 0.35], with five imputed studies.

Figure J3. *Funnel plot for functional recovery*



Note. For functional recovery we found no indication for publication bias, with Egger's test nonsignificant (p = 0.74). Adjusting for publication bias through the Duval and Tweedie's trim and fill procedure resulted in effect size g = 0.09, 95% CI [-0.01, 0.19], with one imputed study.

Nederlandse Samenvatting

De studies die beschreven zijn in dit proefschrift gaan over twee elementen in de weg naar herstel bij depressie: ervaringskennis en lotgenotencontact (de Engelse term wordt in Nederland ook veel gebruikt: *peer support*). We beginnen dit hoofdstuk met een korte samenvatting van de achtergrond en de centrale begrippen in deze thesis (hoofdstuk 1). Daarna vatten we de bevindingen per hoofdstuk samen (hoofdstuk 2 t/m 5). We sluiten af met discussiepunten, de sterke punten en beperkingen van de studies, formuleren aanbevelingen voor vervolgonderzoek en gaan tot slot in op de implicaties voor de klinische praktijk (hoofdstuk 6).

Hoofdstuk 1: *Algemene introductie*

Depressie

We spreken van een depressie wanneer iemand langdurig somber is en geen plezier meer ervaart. Deze klachten zijn dermate ernstig dat ze iemands leven en functioneren beïnvloeden. Ook klachten zoals gewichtstoename of gewichtsverlies, slaapproblemen, gevoelens van waardeloosheid of buitensporige schuldgevoelens, concentratie- en geheugenproblemen of gedachten aan de dood zijn kenmerken van een depressie. De diagnose depressie wordt gegeven wanneer er aan criteria van dit psychiatrische ziektebeeld wordt voldaan (zoals omschreven in de DSM-V, het psychiatrische classificatiesysteem; American Psychiatric Association, 2013). Er zijn verschillende effectieve behandelingen voor een depressie, zoals medicatie of psychotherapie (Cuijpers et al., 2020). Echter, 50% van de mensen die een dergelijke behandeling volgen knapt niet voldoende op (Rush et al., 2006). Depressie wordt gekenmerkt door hoge terugvalcijfers, 40% ervaart een terugval vier jaar na de behandeling (Steinert, Hofmann, Kruse, & Leichsenring, 2014) en 20% ontwikkelt een chronische depressie (dat wil zeggen dat de depressieve klachten gedurende twee of meer jaar aanhouden; Penninx et al., 2011). Door aanhoudende klachten en het grillige beloop van een depressie moeten patiënten leren omgaan met de aandoening in het dagelijks leven. Dit proefschrift gaat in op deze zogenoemde 'weg naar herstel': Wat leren mensen met depressie tijdens dit herstelpad, wat ervaren zij als behulpzaam en helpt lotgenotencontact?

Herstel

Voorheen werd herstel bij depressie met name opgevat als een afname van de bovengenoemde symptomen, ook wel klachtenreductie of *klinisch herstel* genoemd. De laatste jaren is er echter steeds meer aandacht voor andere aspecten van herstel, waarin het omgaan met klachten centraal staat. Deze zogenoemde "herstelgerichte benadering" gaat uit van de kracht en mogelijkheid van het individu. Het leiden van een zinvol leven met kwetsbaarheden en beperkingen staat centraal. In deze benadering worden *persoonlijk herstel* en *functioneel herstel* onderscheiden. Persoonlijk herstel wordt gezien als “een individueel proces gericht op het hervinden van de persoonlijke identiteit en het hernemen van de regie op het leven” (Anthony, 1993, p. 527). Thema’s als hoop, verbondenheid met anderen, en grip op het eigen leven staan centraal (GGZ-standaarden, 2019; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). *Functioneel herstel* gaat in op het maatschappelijk functioneren: het ontwikkelen en hernemen van sociale rollen in het dagelijks leven, zoals werk, studie en vrijetijdsbesteding (GGZ-standaarden, 2019; Van der Stel, 2015). De herstelgerichte visie gaat er vanuit dat herstel een voortdurend proces is, een weg die wordt afgelegd waarin mensen leren wat hen helpt. Hoewel deze visie inmiddels wereldwijd ondersteund wordt (WHO, 2013; 2021) is er nog weinig bekend over wat mensen met depressie zelf ervaren en leren in de weg naar herstel. Het is daarom belangrijk om het perspectief van de patiënt te betrekken in onderzoek (Herrman et al., 2022).

Ervaringskennis

Met het begrip ervaringskennis wordt bedoeld: de persoonlijke kennis en ervaringen die iemand opdoet in het omgaan met de aandoening: wat helpt wel en wat helpt niet in de weg naar herstel? (Boevink, 2017; Borkman, 1976). Deze kennis gaat voor een groot deel over het hervinden van eigen regie in het leven, wat vaak ‘empowerment’ genoemd wordt. Waar empowerment gaat over een gevoel van kracht en regie, kunnen zelfmanagement strategieën gezien worden als een concrete invulling hiervan (Cerezo, Juvé-Udina, & Delgado-Hito, 2016). Wat doen mensen in het dagelijks leven om de depressie te ‘managen’. Voorbeelden hiervan zijn het volgen van een vast dagritme en tijdig om hulp vragen (van Grieken, Kirkenier, Koeter, & Schene, 2014).

Lotgenotencontact

Lotgenotencontact is gebaseerd op het geven en ontvangen van steun of hulp waarbij de eigen ervaring wordt ingezet. De uitwisseling van ervaringskennis staat dus centraal. Er is geen vastomlijnde definitie van lotgenotencontact, maar centrale aspecten zijn: respect, gedeelde verantwoordelijkheid, en overeenstemming wat behulpzaam kan zijn (Mead, 2003). Lotgenotencontact kan als een stigmatiserende term worden ervaren, hiermee wordt bedoeld dat er structureel negatieve kenmerken aan ‘lotgenoten’ wordt toegeschreven. Er is echter geen goede Nederlandse vertaling beschikbaar, daarom hanteren we liever de Engelse term: *peer support*. Er bestaan veel verschillende vormen van peer support, er zijn bijvoorbeeld online en offline initiatieven, die 1-op-1 contact of groepsbijeenkomsten bieden, met een vaste structuur of juist een vrijblijvend, flexibel, karakter. Omdat eHealth steeds belangrijker wordt in de Geestelijke Gezondheidszorg (GGz) krijgen online peer support platforms steeds meer aandacht in de klinische praktijk en onderzoek (Karyotaki et al., 2021; P3NL, 2022).

In dit project ontwikkelden wij een online peer support community voor mensen met depressie, genaamd “Depressie Connect” (DC). Depressie Connect is een digitaal platform waarop mensen met depressie (anoniem) ervaringen kunnen uitwisselen in het omgaan met depressie. We ontwikkelden DC in nauwe samenwerking met de Nederlandse patiëntenvereniging voor depressie, de Depressie Vereniging (Depressie Vereniging, 2022). Deze vereniging host nu het platform met een team van ervaringsdeskundige vrijwilligers. Ook werden in de co-creatie van DC zorgprofessionals (onderzoekers, psychiaters en behandelaren) en naasten van mensen met depressie betrokken. DC is gericht op het toekomstperspectief in het omgaan met depressie en is een besloten en veilig platform, dat na registratie toegankelijk is voor iedereen (Depressie Connect, 2022).

Doel thesis

Hoewel het aantal peer support initiatieven wereldwijd blijft groeien is er relatief weinig onderzoek naar de effectiviteit ervan op de drie belangrijkste domeinen van herstel (klinisch, persoonlijk en functioneel herstel). Ook is er nog weinig bekend over de elementen van peer support die bijdragen aan de werking ervan. Kortom, naast de vraag *of* peer support werkt (de effectiviteit) is er ook aandacht nodig voor de vraag *hoe* peer support werkt (de werkzame elementen). Het doel van deze thesis is te verkennen wat mensen met depressie leren in het omgaan met de aandoening (interviewstudie naar *ervaringskennis,* **hoofdstuk 2**) om vervolgens te bekijken wat het nut is van de uitwisseling van deze ervaringskennis. Dit doen we door de online peer support community voor depressie, Depressie Connect, te evalueren met gebruikers (interviewstudie in **hoofdstuk 3** en vragenlijstenstudie in **hoofdstuk 4**). Tot slot bundelen we de resultaten van bestaande effectiviteitsstudies naar peer support. We zijn hierbij gericht op gerandomiseerde gecontroleerde studies (RCTs) die een groep mensen die deelnemen aan een peer support programma vergelijkt met een groep mensen die geen peer support ontvangen, maar in de zogenoemde controlegroep zitten (systematische review en meta-analyse, in **hoofdstuk 5**). Middels deze methode kunnen we het effect van peer support breder bekijken over verschillende mentale aandoeningen en voor de drie domeinen van herstel. Hieronder vatten we de bevindingen per hoofdstuk samen.

Hoofdstuk 2: *Wat leren mensen met depressie in het omgaan met de aandoening? Hoe ontwikkelt zich ervaringskennis bij depressie?*

In deze studie interviewden we mensen met (aanhoudende/chronische) depressie over hun ervaringen in het omgaan met depressie. We vroegen hen wat zij leerden in het omgaan met de depressie en wat hen hielp om zelfmanagement strategieën te gebruiken. De verhalen lieten drie overkoepelende thema’s zien waar mensen met depressie zelf mee bezig waren (op een zogenoemd *intra*persoonlijk niveau): introspectie (o.a. zelfreflectie), empowerment (o.a. acceptatie van de aandoening) en zelfmanagement (o.a. meedoen aan activiteiten). Daarnaast bleek ook de omgeving, de interactie met anderen (het *inter*persoonlijke niveau) van belang, bijvoorbeeld de mate waarin mensen sociale steun en/of (zelf-)stigma ervaarden. De resultaten lieten zien dat deze thema's zich voortdurend en in interactie met elkaar ontwikkelden en bijdroegen aan de ontwikkeling en lange termijn inzet van zelfmanagement strategieën. Deze diepgaande beschrijving van ervaringskennis laat zien dat een brede kijk op omgaan met depressie belangrijk is.

Hoofdstuk 3: *Welke voordelen ervaren gebruikers van de online peer support community Depressie Connect? Zijn deze ervaringen te relateren aan gebruikersrollen?*

Mogelijke voordelen van deelname aan de online peer support community DC zijn beschreven in hoofdstuk 3. Op basis van interviews met de gebruikers bleek dat mensen met depressie meer *verbondenheid voelden met anderen* door deelname aan online peer support. Daarnaast noemden gebruikers dat zij zich *emotioneel konden ontwikkelen* op het platform door samen met anderen te reflecteren op hun ervaringen met depressie. Deelnemers voelden zich *beter geïnformeerd*, ze hadden een beter idee wat ze konden doen wanneer zij symptomen ervaarden (zelf-effectiviteit) en noemden tot slot dat zij *betekenis konden geven aan hun eigen depressie*, door anderen te helpen met hun persoonlijke ervaring (een onderdeel van empowerment). We identificeerden drie gebruikersrollen in de data: *lezen*, *delen* en *reageren*. Gebruikers leken zich te ontwikkelen van passief naar actief gebruiker door verschillende rollen in te zetten en af te wisselen, passend bij de huidige stemming en fase van de depressie. Met name de interactieve gebruikersrol *reageren* leek gerelateerd aan de voordelen van deelname aan DC. Deelnemers die reageerden voelden zich waardevol door anderen te kunnen helpen met hun eigen ervaring. Hierdoor voelden zij zich krachtiger, ofwel meer 'empowered'. Het meest opvallend was de bevinding dat deelnemers het platform gebruikten als leeromgeving om nieuwe vaardigheden in het omgaan met depressie en sociale vaardigheden voor het echte (offline) dagelijks leven te oefenen.

Hoofdstuk 4: *In welke mate en op welke manier nemen mensen met depressie deel aan de online peer support community Depressie Connect, en zijn deze gebruikerskenmerken gerelateerd aan herstel?*

In deze studie bekeken we of deelname aan Depressie Connect gerelateerd was aan verschillende aspecten van herstel, met empowerment als belangrijkste onderwerp. We vroegen alle nieuwe deelnemers van Depressie Connect op drie momenten (bij aanvang tot zes maanden na aanmelding) vragenlijsten in te vullen over empowerment, zelfmanagement, depressieve symptomen en beperkingen in het dagelijks leven. We brachten het gebruik van DC in kaart door gebruikersstatistieken (totale duur van het gebruik van het platform; aantal bezochte pagina's op DC; aantal geplaatste berichten) van de 301 respondenten te clusteren in vier profielen (door middel van een cluster analyse). Actieve deelname was beperkt tot een kleine groep van gebruikers, slechts 2% van de deelnemers vielen in het hoog gebruikersprofiel, en 10% in het gemiddelde gebruikersprofiel. De data-analyse liet geen significante associatie zien tussen de intensiteit van gebruik en verbeteringen in empowerment en zelfmanagement, en afname in depressieve symptomen en beperkingen. Dit zou erop kunnen duiden dat er geen specifiek en optimaal gebruikersprofiel geïdentificeerd kan worden dat nodig is om voordeel te ervaren van deelname aan peer support. Gebruikers lijken de mate van deelname en de manier waarop ze deelnemen af te stemmen op hun huidige behoefte en hun fase van herstel. Gezien het grillige beloop van depressie zou de mate van gebruik erg kunnen verschillen tussen gebruikers en binnen een specifieke gebruiker over de tijd heen.

Hoofdstuk 5: *Is peer support effectief voor klinisch, persoonlijk en functioneel herstel bij mensen met mentale problemen?*

In dit hoofdstuk beschrijven we de resultaten van een uitgebreide systematische review en meta-analyse, waarin we de resultaten van 28 gerandomiseerde gecontroleerde studies (RCTs) naar peer support interventies (PSIs) bundelden en analyseerden. De PSIs in deze studies werden vergeleken met een controlegroep (deelnemers die niet deelnamen aan peer support maar bijvoorbeeld reguliere professionele behandeling ontvingen of op de wachtlijst hiervoor stonden). We bekeken of deelname aan een PSI, in vergelijking met de controlegroep, direct na de interventie en op langere termijn (6 tot 9 maanden na deelname aan de PSI) geassocieerd werd met verbeteringen in klinisch, persoonlijk en functioneel herstel. We vonden kleine maar significante effecten voor peer support op klinisch herstel op korte en lange termijn, voor persoonlijk herstel op korte termijn, en voor functioneel herstel uitsluitend op lange termijn. Met name patiënten met ernstige mentale aandoeningen (zoals ernstige depressie, psychose en bipolaire stoornissen) leken te profiteren. Voor deze groep waren de resultaten op alle drie de hersteldomeinen direct na de PSI significant. Aanvullende analyses, waarin we verschillen in effect tussen diverse typen interventies, verschillende mentale aandoeningen en controlegroepen bekeken leverden geen significant resultaten op. Dit zijn eerste aanwijzingen dat er universele waarden ten grondslag liggen aan peer support die zorgen voor een overstijgend effect, geldend voor alle type interventies en patiënten. Echter, het aantal studies in deze analyses was beperkt en resultaten staan niet vast. Ook de hoofdbevindingen die laten zien dat deelname aan peer support effectief kan zijn voor herstel moeten voorzichtig geïnterpreteerd worden. De huidige peer support studies kampen met methodologische problemen. Door het informele en vrijblijvende karakter kan er geen protocol opgevolgd worden en zijn er mogelijk veel onbekende factoren van invloed waar geen rekening mee gehouden kan worden in de analyses. Desalniettemin kan op basis van deze resultaten gesteld worden dat deelname aan peer support een nuttige aanvulling kan zijn op professionele behandeling.

Discussie

Universele thema's bij diverse mentale aandoeningen

Eerder onderzoek naar peer support en herstelgerichte thema's zoals empowerment en zelfmanagement lijken vooral gericht op patiënten met ernstige psychiatrische aandoeningen en worden benaderd vanuit een brede herstelgerichte visie (met klinisch, persoonlijk en functioneel hersteldomein). Het CHIME raamwerk (Leamy et al., 2011) is een welbekend kader dat de belangrijkste aspecten van persoonlijk herstel samenvat: verbondenheid met anderen, hoop, identiteit, betekenisgeving en empowerment. Deze aspecten gelden voor een brede groep mensen met mentale problematiek, en zijn vergelijkbaar met thema's die wij vinden onder ervaringskennis bij depressie. Dit zou erop kunnen duiden dat er universele thema's zijn in het omgaan met een mentale aandoening, niet specifiek voor depressie of een andere aandoening. Ook de resultaten van de meta-analyse (hoofdstuk 5) wijzen op deze mogelijke zogenoemde 'transdiagnostische processen': we vinden hier geen verschil in effect van peer support tussen verschillende patiëntgroepen.

Of peer support werkt

De meta-analyse die we beschrijven in hoofdstuk 5 is belangrijk in het onderzoeksveld naar de effectiviteit van peer support. We tonen voor het eerst aan dat peer support effectief is voor symptoomreductie, ofwel klinisch herstel. Eerdere meta-analyses waren specifiek gericht op een bepaalde groep patiënten (bijv. alleen postnatale depressie) of bekeken specifieke vormen van peer support (bijv. alleen 1-op-1 lotgenotencontact). Wij breidden de huidige kennis uit door meer en verschillende peer support studies te betrekken. Zo bevestigen we niet alleen het eerder gevonden effect van peer support op persoonlijk herstel (Lyons, Cooper, & Lloyd-Evans, 2021; White et al., 2020), maar vinden ook effecten voor klinisch herstel. Bovendien bevestigen onze resultaten de bevindingen van meer beschrijvende studies naar peer support, zoals reviews en evaluatiestudies (zie onder andere: Griffiths, Calear, Banfield, & Tam, 2009b; Shalaby & Agyapong, 2020).

Hoe peer support werkt

Als aanvulling op de huidige onderzoeksresultaten over de vraag *hoe* peer support werkt, vinden wij aanwijzingen dat peer support zou kunnen fungeren als leeromgeving. Deelnemers zouden op een online platform de ontwikkeling van hun ervaringskennis kunnen stimuleren. Ook hebben we bekeken of de intensiteit en de kenmerken van gebruik van online peer support geassocieerd zijn met de voordelen van deelname. Overeenkomend met huidige kennis over online communities (van Mierlo, 2014; Carron-Arthur et al., 2014), blijkt slechts een klein deel van de gebruikers het platform intensief te gebruiken (2% hoog-gebruikers, 10% gemiddeld-gebruikers). Hoewel onder de deelnemers van Depressie Connect het niveau van empowerment en zelfmanagement verbeterde over de tijd heen, en depressieve symptomen en beperkingen in het dagelijks leven afnamen, konden we niet terugzien dat dit gerelateerd was aan de mate van gebruik van de online peer support community. Het feit dat deelname aan een online community een vrijblijvend karakter heeft lijkt essentieel: deelnemers kunnen zelf bepalen in welke mate en welke rol zij willen deelnemen. Dit past bij thema's van de herstelgerichte visie, autonomie en eigen regie staan centraal.

Wanneer we de resultaten van onze interviewstudies, vragenlijstenstudie en meta-analyse bundelen zien we dat ervaringskennis en peer support waardevol kunnen zijn tijdens de weg naar herstel bij mentale aandoeningen en specifiek depressie. Er is meer onderzoek nodig naar de processen achter peer support die bijdragen aan de werking ervan: welk type en mate van gebruik is nodig? De mogelijke voordelen rondom de inzet van ervaringskennis en peer support die wij identificeren in onze studies passen bij de huidige ontwikkelingen in de GGz om de omgeving van het individu met mentale problemen te versterken en verbinding te zoeken met de samenleving. Dit is in lijn met de visie van het Ecosysteem Mentale Gezondheid (Furst, Bagheri, & Salvador-Carulla, 2021) en concrete effectief bewezen methoden zoals resource-groepen (Tjaden et al., 2021).

Sterke punten, beperkingen en aanbevelingen voor vervolgonderzoek

Ieder onderzoek heeft sterke en zwakke punten. Een belangrijk sterk punt van ons onderzoek is dat we verschillende methoden gebruikt hebben. De ontwikkeling van ervaringskennis blijkt een dynamisch proces en peer support gaat gepaard met complex samenhangende processen. Om het nut en de werking ervan goed in kaart te kunnen brengen, is het belangrijk deze kwestie op verschillende manieren te bekijken. Wij deden dit door interviews en vragenlijsten af te nemen, en resultaten van bestaande onderzoeken (RCTs) te bundelen en te analyseren in een meta-analyse. Daarnaast brachten we verschillende partijen bij elkaar in dit project. De samenwerking tussen de GGz en patiëntenorganisatie is uniek en heeft geleid tot een gezamenlijk en duurzaam te implementeren innovatie (DC) wat de basis vormt voor verdere gezamenlijke projecten. Dit is een tweede sterk punt van dit onderzoek.

Een minder sterk punt is de beperkte generaliseerbaarheid van de resultaten. Ten eerste hebben we ons in beiden interviewstudies en de vragenlijst studie met name gericht op mensen met aanhoudende depressieve klachten. Bovendien bleken de respondenten bijna altijd professionele behandeling te ontvangen. Daarnaast is het mogelijk dat er vooral mensen hebben deelgenomen die positief tegenover peer support en ervaringskennis staan, wat tot positieve vertekening van de resultaten kan leiden. Echter, de resultaten van de meta-analyse laten robuuste effectieve resultaten zien voor peer support. Er blijft nog veel onduidelijk over de werking van peer support. De studies van deze thesis suggereren dat een flexibel gebruik met afwisselende intensiteit en gebruikersrollen (lezen, delen, en reageren) een belangrijk kenmerk is van online peer support. Nader onderzoek moet dit echter uitwijzen. Om de mate en het type van gebruik goed in kaart te brengen, zouden ook aspecten als de inhoud van de berichten en het aantal reacties dat een deelnemer ontvangt in toekomstig onderzoek geïntegreerd moeten worden.

Een duidelijke beperking is dat ons vragenlijst onderzoek geen controlegroep had. We kunnen daarom geen duidelijke uitspraken doen over het effect van deelname aan DC. We weten niet of de daling op symptomen en stijging op empowerment door het gebruik van DC komt en met een controlegroep ook te zien was geweest. Kortom, de resultaten van deze thesis zijn vooral verkennend. Toekomstig onderzoek zou een controlegroep kunnen organiseren. Bovendien kunnen de processen van peer support en herstel in kaart worden gebracht door specifieke deelnemers langdurig te volgen met frequente metingen die verschillende typen data opleveren: kwalitatief (tekst, zoals uitgetypte interviews of berichten geplaatst op een peer support platform) en kwantitatief (cijfers, scores op vragenlijsten die ingaan op herstel en gebruikersstatistieken). Als aanvulling op brede herstel-concepten zoals empowerment, zou toekomstig onderzoek rondom peer support specifiekere thema's in de weg naar herstel, zoals 'hoop', kunnen evalueren. Tot slot zou onderzoek zich kunnen richten op de inzet van online aangeleerde vaardigheden in de offline wereld door participatie in het dagelijks leven aan te moedigen in de PSI en vervolgens te evalueren.

Implicaties voor de klinische praktijk

Het raamwerk voor ervaringskennis, waarin we de belangrijkste thema's illustreren bij de ontwikkeling van dit type kennis, kan professionals en patiënten een handvat geven om samen te verkennen wat de thema's betekenen voor de patiënt en hoe de ontwikkeling hiervan gestimuleerd kan worden. Peer support kan hierbij als mogelijkheid tot extra ondersteuning genoemd worden. Omdat we vinden dat deelname aan peer support effectief kan zijn op de verschillend hersteldomeinen kunnen behandelaren in de GGz, maar ook huisartsen en medewerkers van herstelgerichte initiatieven mensen met depressie verwijzen naar peer support initiatieven. Dit vergroot mogelijkheden voor patiënten om te werken aan herstel en te oefenen met het omgaan met de aandoening.

Tot slot laat deze thesis zien dat de balans tussen ervaringskennis, professionele kennis en wetenschappelijke kennis belangrijk is en elkaar kunnen versterken om zo tot de beste zorg te komen voor de persoon met depressie. Naast inzet van bewezen effectieve behandelingen voor depressie (wetenschappelijk kennis) kan de professional de patiënt aanmoedigen om eigen regie te nemen bij herstel van depressie (professionele kennis) zodat hij of zij kennis kan ontwikkelen wat helpt in het omgaan met depressie, passend bij persoonlijke behoefte en voorkeuren (ervaringskennis). In deze driehoekssamenwerking kunnen de partijen leren van elkaar en tot eenzelfde taal komen. Daarnaast zou een betere samenwerking tussen GGz-instellingen, patiëntenorganisaties en lokale herstelinitiatieven in het sociale domein kunnen leiden tot een betere plek voor peer support in het huidige Nederlandse zorglandschap.

Conclusie

In dit proefschrift beschrijven we voordelen van ervaringskennis en peer support bij depressie en andere mentale problemen. We vinden bewijs voor het effect van peer support op klinisch en persoonlijk herstel. Professionals kunnen hun patiënten wijzen op de mogelijkheid deel te nemen aan peer support, als aanvulling op de behandeling. Mensen met depressie lijken te profiteren van het vrijblijvende karakter van online peer support omdat zij de mate en het type gebruik kunnen afstemmen op hun huidige stemming en fase van herstel. Er is meer onderzoek nodig om dit flexibele gebruik in kaart te brengen, om zo beter inzicht te krijgen hoe peer support werkt. Overkoepelend laat dit proefschrift zien dat ervaringskennis een belangrijke kennisbron is die gebruikt en toegepast kan worden in de huidige zorg voor depressie. Peer support kan een laagdrempelige interventie zijn om dit mogelijk te maken.

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Curriculum Vitae

Dorien Smit was born on August 18 1987 in Breda, the Netherlands. In 2005 she completed her secondary education at the Mencia de Mendoza Lyceum in Breda and started the study Health Sciences at Maastricht University, with the specialization track Mental Health Sciences. After receiving her bachelor degree, she completed two Master's degrees in Social Sciences at Utrecht University, one programme for Youth Studies, and the other for Clinical Child, Family and Education Studies [Orthopedagogiek]. She completed her studies in 2012 and started working in clinical practice as a behavioral scientist for adolescents, and as a counsellor for students with autism. She gained experience in several settings for psychosocial support and mental wellbeing, and worked in a youth detention center [RJJI Den Hey-Acker, Breda], in a mental health supported accommodation service for students [JADOS, supported living for students with autism, Utrecht], and in a health care institution for (homeless) adolescents and young adolescents with multiple problems [AHRA, Amersfoort]. In March 2018 she started as a junior scientific researcher at the mental health care institution Pro Persona and as an external PhD-candidate at the Radboud University Nijmegen. From March 2018 until June 2022 she worked on her project, "The Power of Depression", at Pro Persona in a unique collaboration with the Dutch Depression Association, and the Radboud University Medical Center. She investigated the development of experiential knowledge in depression, and developed an online peer support community for depression together with the patient association. Subsequently, she examined potential benefits and working mechanisms of engaging in peer support. Begin 2022, Dorien and her colleagues from the mental health care institution Pro Persona, the Dutch Depression Association, Radboud University Medical Center, and a new stakeholder: Ixta Noa (a social organization for adults coping with psychological vulnerabilities), received a collaborative grant of ZonMw (the Dutch organization for health research and health innovation), to conduct a follow-up project, "The Power of Peers". In this research, we further investigate the development of the recovery pathway and the benefits of peer support in depression. We expand our scope including functional (i.e., societal) recovery, and extend the joint venture through working together with recovery initiatives in the Netherlands, with Ixta Noa and the Dutch Depression Association as central parties. Dorien has been working as a post-doctoral researcher at Pro Persona, focusing on the role of peer support in (personal and functional) recovery and implementing peer support in clinical practice.

List of Publications

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Smit, D., Peelen, J., Vrijsen, J. N., & Spijker, J. (2020). An exploration of the conditions for deploying self-management strategies: a qualitative study of experiential knowledge in depression. *BMC psychiatry*, *20*(1), 1-11. doi: 10.1186/s12888-020-02559-3

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