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# Interventions targeting identity: a protocol for a transdiagnostic scoping review with implications for adults with a severe mental illness

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## Abstract

**Objective:** The main aim of the review is to explore interventions that target identity and self-concept in different patient groups, including people with severe mental illnesses, acquired brain injury and intellectual disability. A second objective is to discuss the implications of these results for the treatment of people with severe mental illness. The field of mental health care might benefit from a transdiagnostic approach, and especially from interventions targeting different groups of people who often cope with identity challenges and/or cognitive difficulties.

**Introduction:** People with a (severe) mental illness, acquired brain injury or intellectual disability often face identity challenges, for example because of stigma, the impact of illness-roles, cognitive deficits and difficulties with social integration. The illness experience

and the associated losses can impact identity-development and provoke a focus on illness-related self-concepts. Strengthening of a more balanced identity is central to recovery-oriented care. The current systematic scoping review provides a transdiagnostic perspective on interventions that aim to broaden and develop multifaceted identities.

**Inclusion criteria:** Included studies target identity with interventions for adults with a severe mental illness, schizophrenia, psychosis, bipolar disorder, severe psychotic depression, acquired brain injury or intellectual disability. Studies should be peer-reviewed and should have a pre-specified aim to help individuals to develop, broaden, rebuild or reflect about multiple aspects of their identity and/or self-concept. No specific further inclusion criteria were formulated regarding study-design or intervention type, to ensure a broad range of studies.

**Methods:** Studies related to identity, self-concept, illness-identity and “illness engulfment” will be searched in a broad range of databases. Qualitative and quantitative data regarding the program mechanisms and content, theoretical background, experiences and outcomes of interventions will be extracted and described.

## Introduction

### Identity through the life-span

Identity refers to who an individual is as a person, which is connected to someone's self-views, self-defining characteristics and cultural, social- or personal self-concepts. Self-views are multifaceted, and comprise personal identities, as well as social and cultural identities, and role-identities (Owens et al., 2010; Tajfel & Turner, 1979). Importantly, the understanding of the concept of identity may differ between cultures, subgroups, mental health disciplines and researchers from different ‘scientific paradigms’. In the context of this review, we refer to self-identity as the implicit or explicit views people consider to be central about themselves as persons in various contexts, that is, the multifaceted identities that are important in their self-concept. In line with the theories of William James (1890), this descriptive identity (the ‘me’) can theoretically be distinguished from the phenomenological experience of the self-as-subject (the ‘I’), and from self-evaluative feelings, such as shame or self-esteem. In general, self-identity is at play in all the reactions to the question: “Who am I?”. The answers to this self-reflective question might come in the form of self-referent labels, such as names, roles, characteristics, gender, worldviews, life goals, interests, cultural

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background or relations to other people. Additionally, people can construct stories about these self-aspects, and integrate the important narratives into meaningful life-stories that help to find meaning and purpose in life and build a coherent self-identity (McAdams, 1985; McLean et al., 2007). Throughout the life-span people develop their identities, and change their self-views and the way in which they relate to these self-aspects, as new identities emerge, become more salient, or get lost with new life-experiences (Ownsworth, 2014; McLean et al., 2007). With this dynamic understanding of identity as meaningful and changeable in mind, it becomes relevant to look at groups of people who often face challenging life-experiences that may substantially impact their identity.

### **Identity challenges and severe mental illness**

People with a severe mental illness (SMI) suffer from enduring psychiatric illnesses that have a high impact on their health care needs, daily life functioning and self-views (Conneely et al., 2021; Delespaul et al., 2013). The diagnoses that are most prominently represented in the SMI group include schizophrenia, psychotic spectrum disorders and enduring bipolar or psychotic depression (Delespaul et al., 2013). Although the life-time prevalence of these disorders is estimated to be relatively low (Moreno-Küstner; Perälä et al., 2007), the disability burden is disproportionately high (James et al., 2018). This is reflected in lengthy hospitalisations (Killaspy, 2014) and high societal costs (Desai et al., 2013; Jin & Mosweu, 2017). The disability-burden of SMI is not only caused by the psychiatric symptoms, but also by disabilities and difficulties encountered in multiple life-domains. For example, many people with SMI cope with social isolation, unemployment, health disparities, cognitive impairments, loneliness (Morgan et al., 2014; 2017), and feelings of helplessness and existential distress due to demoralization (Berardelli et al., 2019). These illness-experiences impact the way in which people with SMI view their world and themselves, often resulting in challenges to their identity (Kaite et al., 2015).

According to a recent systematic review by Conneely et al. (2021), negative identity-changes often occur due to clinical symptoms, cognitive dysfunctions, (social) losses and stigma during and after psychosis. The impairments and life changes that accompany SMI, may each impact self-identity in a different way. Firstly, SMI can cause a 'basic self-disturbance', as hallucinations, delusions and other clinical symptoms alter the pre-reflexive first-person experience (Nelson and Raballo, 2015). When the basic self is disturbed, this arguably also influences narrative processes and higher-order self-views. Secondly, the self-view can be influenced by autobiographical memory deficits (Berna et al., 2016; Ricarte et al., 2017),

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changes in self-reflective processing (Van der Meer et al., 2013) and metacognition, i.e., the impaired ability to integrate feelings and thoughts about oneself into a complex narrative (Lysaker et al., 2018). Finally, (social) identities are also impacted by common negative experiences and losses associated with difficulties with unemployment, discrimination, stigma, lost and changed social identities and roles, and social isolation (Morgan et al., 2017; Muthert, 2012; Thornicroft et al., 2009). Thus, SMI can be a disruptive experience that impacts identity not only through clinical and cognitive symptoms, but also through secondary negative experiences and social changes.

An internalization of these negative experiences and stigmatized views into one's identity can cause a negative 'illness identity' (Yanos et al., 2010, Yanos et al., 2020). Illness engulfment can occur when this narrowly defined illness-centered identity becomes predominant in the self-concept (McCay et al., 2007). A person who is 'engulfed in illness' acts mostly according to a patient-role and loses old identities and behaviors that do not fit with this illness-role (Lally, 1989; McCay & Seeman, 1998; McCay et al., 2007). According to people with SMI, the recovery of identity involves moving away from this engulfed and unidimensional illness-identity, to develop a non-stigmatized, positive and multidimensional view on the self (Bird et al., 2014). This does not mean that clinicians should try to help people to ignore or get rid of illness-identities, as the illness is often still an important and integral part of the self-definition (Gwinner et al., 2013). Instead, recovery of identity could mean that people with SMI can integrate the positive and negative aspects of illness-identities, without being engulfed by stigmatized or negative illness-concepts. Additionally, recovery of the self implies that people with SMI can re-develop and broaden their view of themselves, so that other social roles, interests, goals, personal meanings and self-characteristics can become salient in their self-view. In some cases, the initial negative identity-changes may also help people to learn about themselves and experience post-traumatic self-growth (Conneely et al., 2020).

In the field of SMI-research, the importance of identity-recovery has been highlighted by the recovery paradigm, which advocates that in addition to 'clinical recovery' it is important to attend to social, functional and existential- or personal recovery (Winsper, 2020). From this perspective, personal recovery is often described as "(...) a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness." (Anthony, 1993, p. 15). Thus, personal recovery is considered as an active process, which involves

coping with the effects of shattered dreams and losses, and recovering a sense of self and purpose (Anthony, 1993; Deegan, 1998). Recovery of self and identity is also one of five themes from the 'CHIME' recovery framework, with CHIME being an acronym for "connectedness; hope and optimism about the future; identity; meaning in life; and empowerment" (Leamy et al., 2011).

### **Focus of the scoping review**

Despite the growing attention for identity-recovery, a recent review about recovery-oriented studies did not find any intervention studies that evaluated identity outcomes with quantitative measures (Winsper et al., 2020). Therefore, it is important to look at identity-interventions from a broader perspective. In the current review we do this by including qualitative evaluations of intervention studies and by including studies from different theoretical backgrounds. Additionally, the current review also aims to transcend diagnostic boundaries and explore available identity-based strategies and interventions that are not specifically developed for people with SMI, as these interventions could help us to understand which mechanisms facilitate identity in general. The review will therefore also incorporate interventions developed for people with an intellectual disability (ID) and people with an acquired brain injury (ABI).

We realize that individuals with an ID or ABI cope with different life struggles and might also experience identity-issues in a different way than people with a SMI. However, a similarity between the three groups is that many individuals with these illnesses are regularly confronted with stigma (Beart et al., 2005; Conneely et al., 2020; Villa et al., 2020), and cope with social and/or functional challenges that may impact autonomy and participation in society (American Psychiatric Association, 2013). Additionally, we also expect that the literature about interventions for people with an ID or ABI might take into account the cognitive disabilities of the participants in the design of the intervention. This is relevant for the SMI target group, as intellectual and cognitive impairments are highly prevalent in the most seriously impaired people with SMI (Morgan et al., 2008; Morgan et al., 2014; Palmer et al., 2009), and may impact uptake and understanding of interventions.

As far as we know, no other systematic or scoping reviews have been published or registered with this specific transdiagnostic focus. This was checked with a preliminary search in March 2021 (in CRD, Dopher, Prosperio, the Cochrane database, APA Psycinfo, Academic search premier, CINAHL, Medline, the Psychology and behavioral sciences

collection and JBI Evidence Synthesis). A related systematic review has focused on intervention studies that measure self-concept or self-esteem in the context of traumatic brain injuries (Ownsworth & Haslam, 2016). The difference with the current study is that we also focus on other acquired brain injuries and on studies with a qualitative evaluation of identity. Unlike the review by Ownsworth et al (2016), the current review does not include studies that only focus on self-esteem. Another related review focuses on self-stigma interventions in people with SMI (Yanos et al., 2015), but this review did not systematically include all the available interventions aiming at self-identity.

Because it is yet unclear how much and what kind of evidence is available, and because we want to give a broad overview of the literature without doing a meta-analysis of effectiveness, we feel a scoping review is most suitable. A scoping review can be used to systematically map the available literature about a certain topic, especially if the scope of the review is not limited to a single precise research question (Munn et al., 2018).

The goal of this review is twofold. The main aim of the current review is to create an overview of available interventions that target the development and reconstruction of identity or self-concept in people with acquired brain injury, intellectual disability, and SMI. For this purpose, the review summarizes information with regards to successful and unsuccessful intervention strategies, intervention outcomes, user experiences, as well as the theoretical background of these studies in the three patient groups. A second aim is to discuss how these results could inform the treatment and support specifically for people with SMI, which may support the development of new interventions.

## Review questions

1. What are the available interventions that target identity in people with (a) a severe mental illness, (b) an intellectual disability, or (c) an acquired brain injury?
  - a) What are the aims of these interventions?
  - b) What is the content of these interventions (e.g. key components)?
  - c) What are the theoretical assumptions (e.g. underlying theories, mechanisms or interpretations of the concept of identity) of the studies?
  - d) What are the (qualitative and quantitative) outcomes of these interventions?
2. What can researchers and therapists in the field of severe mental illnesses learn from identity-based interventions developed specifically for people with a cognitive deficit, such as a brain injury or an intellectual disability?

## Keywords

*Severe Mental Illness; Personal Recovery; Identity; Self-concept; Intervention*

## Eligibility criteria

### Participants

This review has a transdiagnostic focus, with three broad categories of target groups. Articles do not have to provide information about the diagnostic classification process. At minimum, 50% of the participants should fall within one of the following categories:

- a) SMI or psychotic disorder: Participants have a primary diagnosis of a psychotic disorder, schizophrenia, bipolar disorder, psychotic depression or severe mental illness (not specified).
- b) ABI: Participants have an acquired brain injury (including traumatic as well as non-traumatic brain injuries).
- c) ID: The major focus of the study is on participants who have an intellectual disability (intellectual developmental disorder). We define an intellectual disability, in accordance with the DSM-5 criteria, as a disorder characterized by deficits in intellectual and adaptive functioning that have an onset in the developmental period (American Psychiatric Association, 2013).

Only studies with a clinical adult (aged 18 or older) sample will be included. The decision to limit the target group to adults only was made during the process of the title/abstract screening. The reason to limit our search to adults only was because the articles about self-concept in children seemed to be (a) very different from interventions in adult populations, (b) often in the context of schools and referring to academic self-concepts and (c) and therefore less relevant for the main aim of our review.

### Concept

The main focus of the review is on studies that explicitly aim to focus on developing, broadening, rebuilding or reflecting about identity, self-concept or a relevant synonym. Identity should be a prespecified aim of the intervention study, either because the intervention clearly aims to impact identity, or because the impact of the intervention on identity is formally evaluated. A definitions document will guide the discussion about relevance of the studies.

Identity is a topic that overlaps partly with many other concepts, such as metacognition, stigma, meaning in life, growth, self-esteem, pre-reflexive 'sense of self', and agency. These concepts may be part of the identity, but also refer to other concepts outside the identity-literature. In order to contain the review, studies about these related topics are only included if they explicitly mention identity as an aim. In line with our view of identity as multifaceted, the current review does not cover studies that highly focus on one particular aspect of identity, such as gender identity, physical identity or occupational identity. Similarly, interventions that merely focus on counteracting negative stereotypes or (self)-stigma without helping people to develop and reflect upon other identity-aspects, will be excluded.

### **Context**

This review will consider different types of interventions and settings (for example: psychotherapy, spiritual care, serious games, eHealth, in-patient setting, self-care, peer-support etc.). Only interventions that are evaluated (quantitatively or qualitatively) in the study will be included. Soon after the title/abstract screening began we also decided to exclude studies that discuss general health care practices (e.g. hospitalization or rehabilitation) and a-specific treatments (e.g. psychotherapy or physiotherapy in general), as these do not fit with our aim to focus on studies that describe specific interventions that target identity.

### **Types of Sources**

This scoping review will consider experimental and quasi-experimental intervention studies that provide qualitative or quantitative information about outcome or usability, including randomized controlled trials, non-randomized controlled trials, before and after studies, and other clinical trials or experimental pilot studies. Additionally, qualitative studies that primarily focus on evaluations of a specific intervention or programme can also be included. Only peer-reviewed articles will be included. Articles will not be excluded based on quality appraisal, as the goal is to map the state-of-the art in the literature and generate hypotheses about potential outcomes and factors. As we are interested in intervention studies, we will only include original research, and exclude text and opinion papers, editorials, conference abstracts, book chapters, theoretical articles and reviews. Articles will not be excluded based on language, however only English search terms will be used. Studies that cannot be translated by the reviewers will be mentioned, but not used in the synthesis.

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## Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews (Peters et al., 2020) and written according to the Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) guidelines (Tricco et al., 2018). Team meetings will be used to discuss the review process. The team includes researchers who represent different perspectives that are important for this project (including researchers in Psychology, Psychiatry, Spiritual care and an experience expert). The protocol will be registered online.

### Search strategy

The review will summarize the results from published peer-reviewed primary studies, and the search strategy is tailored to this question. In addition to peer-reviewed articles, this review will also locate doctoral dissertations, which are only used for cross-referencing. An information specialist was consulted to help with the development of a first search strategy, which was based upon primary studies and identity-related reviews. Additional key-words were found by screening the title, abstract and index-terms of MEDLINE and PsycInfo hits, until saturation was reached after 400 articles. We aimed for a comprehensive search strategy, which was developed during a process of several weeks, during which the search was checked and adapted iteratively and discussed in several team meetings. The final search strategy can be found in Appendix I. This strategy aims to find a combination of three search strings, with S1) words or word-combinations related to 'identity', 'self', 'engulfment' and 'self-concept' S2) words related to interventions, or words that are often used in studies that describe or evaluate interventions and S3) search terms describing the different target groups. The second and third search string include index terms. Index terms were not used for S1, as many databases used the identity-related index terms in such a broad way that too much irrelevant literature would be retrieved with these terms.

The databases to be searched include PsycInfo, the Psychology and Behavioral Sciences Collection, Medline, CINAHL, Academic Search Premier, EBSCO open dissertations, and Web of Science, and will be retrieved with EBSCO host or Web of Science. Relevant databases were identified by checking other reviews and review-protocols and by checking which databases added relevant articles that could not be retrieved with PsycInfo or Medline only. We expected that religion-related databases could provide articles about identity-based methods in spiritual care, but initial searches in the Atla Religion Database and Index Theologicus did not provide relevant (experimental) studies. We will also consult other

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researchers in the field, through existing networks of experts and researchers (such as the Recovery Research Network), to identify additional interventions. Reference tracking and, if possible, a forward citation search will be used to identify additional studies.

### **Study selection**

Citations will be deduplicated in Excel through automatic functions, followed by a manual check of duplicates in Rayyan (Ouzzani et al., 2016). Study selection will be done in blinded mode in Rayyan, by the first author and a research assistant. For this purpose, we will use a decision flow chart (Appendix II), and a definitions document, that delineates the relationships and boundaries between related concepts. For a pilot test of the decision rules, a random sample of 25 articles will be selected and screened blindly by the first author and two research assistants. This process will be repeated until the interrater agreement between the three researchers about the initial screening decisions ('included for full text screening', 'excluded' or 'maybe') is at least 75 percent. Disagreements will be discussed in the team and where needed the guiding documents will be adapted, or a purposeful sample of studies can be selected for training purposes.

Following the pilot test, titles and abstracts will then be screened in blinded mode by two independent reviewers (research assistant and first author). Any disagreements will be resolved by consultations with a third reviewer or the whole research team. A consensus-meeting with the whole team can be planned in case an unanimous decision cannot be made by the two independent reviewers after full text screening, for example because the reviewers are not sure if the topic of the articles matches our research questions. The process of study retrieval, deduplication and selection, will be reported in the final scoping review through the Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram (Tricco et al., 2018), which will include a list with reasons for exclusion for the articles that were retrieved for full text screening.

In accordance with the scoping review guidelines by Arksey and O'Malley (2005), studies will be discussed in our review regardless of methodological quality. Petticrew (2015) notes that 'low quality studies' might have a different focus than 'high quality studies', and can be of value in a rapidly developing field, for example because it can help to build theory and show potential effects that need further testing. As the goal of our review is exploratory and

hypothesis-generating, a study selection based on the appraisal of methodological quality or risk of bias is not necessary in the context of the current review.

### **Data Extraction**

Data-extraction will be performed only for articles written in English or Dutch. For the process of extracting and ordering relevant quantitative and qualitative information a data-extraction tool was developed by the first author and checked by the whole review team. The tool is partly based on the Template for Intervention Description and Replication checklist (TIDieR) developed by Hoffmann et al. (2014). The extracted data includes specific details about the participants, study methods, intervention components, outcomes and theoretical background, thereby also providing a framework for qualitative data-extraction. The tool also provides reflective questions to help the reviewer to form a comprehensive and critical understanding of the studies. For example, the form prompts the reviewer to think about contextual factors, possible mechanisms and applicability of this study for people with cognitive deficits. Furthermore, the data-extraction form provides the reviewers with a deductive framework with questions about other recovery related topics, based upon the CHIME (Connectedness, Hope, Identity, Meaning, Empowerment) framework described by Leamy et al. (2011). The draft extraction form can be found in Appendix III.

Two independent reviewers will pilot the data-extraction form after the study selection, using a purposive sample of the studies to be reviewed. During the process of data extraction, the form will be revised as necessary, in accordance with the iterative process of a scoping review. Major modifications to the data-extraction form will be described in the scoping review, and both the initial and the final form will be made available to the readers in an online Appendix. Data will be extracted by two independent reviewers. Any disagreements that arise between the reviewers will be resolved through discussion. If necessary, corresponding authors will be contacted to provide additional information.

### **Data Analysis and Presentation**

Qualitative as well as quantitative data will be extracted with the data-extraction form (Appendix III). Qualitative findings will be extracted in an inclusive way, as information that is not presented as a direct quotation will also be taken into account.

The data extracted with the data-extraction form will be described in one or more tables and a narrative summary. The data-extraction form includes more information than the data that

can be described in the tables, including subjective notes, deductive questions about topics (e.g. CHIME-framework), and notes about untested mechanisms and hypotheses. This additional information will be used to get an overview of the differences between the studies, and the possible barriers and facilitators of identity-development, which can inform the narrative summary and discussion section of the review.

The tables will describe at minimum: intervention name, study design, intervention and control group, intervention design and components, measures and outcomes. The review will also provide a summary of the theoretical background of the studies, focusing mainly on the assumptions of the authors about identity and the supposed relation between identity and the interventions. Depending on the number (comparable) studies, the team will discuss whether additional charting methods or evidence maps are relevant and viable.

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## Conflicts of interest

There is no conflict of interest in this project.

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## Appendices

The full search strategy, decision tree, and the first version of the data extraction document are presented in the supplementary appendices (Appendix I, II and III).