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# Evaluating the efficacy of 'Coming Out Proud', a group-based intervention to facilitate disclosure and decrease the self-stigma of mental illness

**Submission date**
22/12/2012

**Recruitment status**
No longer recruiting

**Registration date**
24/01/2013

**Overall study status**
Completed

**Last Edited**
25/08/2015

**Condition category**
Mental and Behavioural Disorders

[ ] Prospectively registered
[ ] Protocol
[ ] Statistical analysis plan
[X] Results
[ ] Individual participant data

## Plain English summary of protocol

Background and study aims
Many people with mental illness suffer from stigma and discrimination. As a consequence, many decide to keep their mental illness a secret. Secrecy can help to avoid being discriminated against by others, but it can also be a burden and may be associated with self-stigma (that is agreeing with prejudices against people with mental illness and turning them against oneself), loss of self-esteem, shame and demoralization. In this study we aim to evaluate whether a group program run by people with mental illness (peers) for other peers helps to reduce self-stigma and makes it easier for participants to handle the necessary choices related to secrecy versus disclosure.

Who can participate?
Any adult (18 years or older) person with mental illness, male or female (except those with only substance-related disorders) who feel that secrecy/disclosure is an issue for him or her.

What does the study involve?
We will compare how participants in the group program are doing over time versus participants who are not in this group program. All participants, whether in the group program or not, continue their current mental health service use, if they have any. The group program runs for three weeks, one evening per week and two hours per evening. There are between six and nine participants in each group. Once they have agreed to participate in the study, participants are assigned by chance to either the group program or the control group (which does not have the group program). Using a set of questionnaires, we will assess how people are doing in terms of self-stigma and other outcomes three times: at the very start, and then again three and six weeks later.

What are the possible benefits and risks of participating?
Participants have two possible benefits. First, all participants (whether in the treatment or the control group) may find the questionnaires stimulating and helpful, because they raise issues

relevant to disclosure and related topics. Second, participants in the treatment group are likely to benefit from the discussions with other participants and the group facilitators. All participants will fill in questionnaires offering the chance to reflect upon issues like secrecy, disclosure and ways of coping with stigma. However, some people may find it distressing to think about these issues. Therefore all participants can interrupt or end their participation altogether at any time. Participants in the group program may find it helpful for their choices regarding secrecy, disclosure and coping with stigma. If participants find the group discussions distressing, they can either find support from group members and facilitators or contact the crisis intervention center in our department at any time.

Where is the study run from?
The study takes place at the Psychiatric University Hospital Zürich, Switzerland, in a building in the city center of Zürich mainly dedicated to outpatient and day clinic services. With this hospital as a lead center, the study is conducted in close collaboration with the Institute of Psychology, University of Zürich, and the psychiatric hospital Sanatorium Kilchberg in the Zürich region.

When is the study starting and how long is it expected to run for?
The study started in November 2012 and is expected to run approximately until May 2013, with recruitment of new participants ending approximately in April 2013.

Who is funding the study?
The study is funded by the Psychiatric University Hospital Zürich, Switzerland; by the Sanatorium Kilchberg, Switzerland; and by the Illinois Institute of Technology, Chicago, USA.

Who is the main contact?
Dr. Nicolas Rüsch
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# Contact information

### Type(s)
Scientific

### Contact name
Dr Nicolas Rüsch

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# Additional identifiers

### EudraCT/CTIS number

### IRAS number

### ClinicalTrials.gov number

### Secondary identifying numbers
N/A

# Study information

### Scientific Title
Evaluating the efficacy of 'Coming Out Proud', a group-based intervention to facilitate disclosure and decrease the self-stigma of mental illness: a randomized controlled trial

### Study objectives
1. Determine that the intervention reduces self-stigma among participants in the group program as compared to the control group. We expect that the intervention will reduce self-stigma as compared to the control group, both at the end of the intervention (T1) and at 3-week follow-up (T2).
2. Determine that the intervention reduces distress associated with disclosure, shame, secrecy, social withdrawal, stigma-related stress and stigma as a barrier to seek help, as compared to the control group. Our hypothesis is that the intervention will alleviate stigma's negative impact on individuals in terms of reduced shame, secrecy, withdrawal and stigma-stress as compared to the control group, both at the end of the intervention (T1) and at 3-week follow-up (T2).
3. Determine that the intervention increases empowerment, self-esteem, disclosure-related self-efficacy and quality of life as compared to the control group. We expect that the intervention will strengthen individuals in coping with their mental illness and potential negative societal reactions, i.e. increase empowerment, self-esteem, self-efficacy and quality of life, as compared to the control group, both at the end of the intervention (T1) and at 3-week follow-up (T2).

### Ethics approval required
Old ethics approval format

### Ethics approval(s)
The regional ethics committee of Zürich, Switzerland (Kantonale Ethikkommission), 01/06/2012, ref: EK: KEZ-ZH-Nr 2012-0138

### Study design
Randomized controlled trial

### Primary study design
Interventional

### Secondary study design
Randomised controlled trial

### Study setting(s)
Hospital

### Study type(s)
Treatment

### Participant information sheet

Not available in web format, please use the contact details below to request a patient information sheet

## Health condition(s) or problem(s) studied
People with mental illness (except those with only substance-related diagnoses)

## Interventions
1. Control group

2. Intervention group: The group program is about disclosure ('coming out') versus secrecy of one's mental illness. The groups are facilitated by peers (people with mental illness). Each group runs for three weeks, one evening per week, and two hours per evening.

The intervention contains three lessons, one for each two-hour session.
1. Considering the Pros and Cons of Disclosing:
In this lesson, participants will first discuss their idea of identity and mental illness so that they can decide how to frame their identity. Second, they will discuss how secrets are a part of everyone's lives so that they can decide whether their experiences with mental illness should or should not be disclosed. Third, participants in the group will weigh costs and benefits of coming out in order to facilitate a decision on whether to disclose.
2. There are different ways to disclose:
In this part, people in the group first discuss different levels of (non-) disclosure, ranging from social avoidance and complete secrecy to in-discriminant disclosure and broadcasting one's experience and learn how to weigh the costs and benefits of each. Second, they will learn how to find people that are better to disclose to than others and how to 'test them out' before a potential disclosure in order to see how they think about mental illness before disclosing to them oneself. Third, participants will discuss how others might respond to their disclosure and how that will affect them.
3. Telling your story:
Here, the persons in the group learn how to tell their story in a personally meaningful way, how to identify peers who might help them with the coming out process, to review how telling their story felt, and finally to put together all they learned.

Note that all lessons are accompanied by stories and worksheets in the workbook.

## Intervention Type
Behavioural

## Primary outcome measure
Change of total ISMI (Internalized Stigma of Mental Illness Inventory) score between t0 and t1 in the treatment group as compared to the control group

## Secondary outcome measures
We expect positive variables (such as quality of life, self-esteem) to increase due to the intervention; and negative outcomes (such as self-stigma) to decrease.

Positive:
1. Empowerment Scale, 28 items (Rogers et al., 1997)
2. Recovery Assessment Scale, 24-item short version (Corrigan et al., 1999)
3. Subjective Quality of Life, 12 items (Kaiser et al., 1999)
4. Rosenberg Self-Esteem Scale, 10 items (Rosenberg, 1965)

5. Disclosure-related self-efficacy, 1 item ('How confident are you to decide and handle well all the issues related to disclosing your mental illness or to keeping it secret?'; from 1, not at all, to 7, very much)
6. Benefits of being out, assessed by the Coming Out with Mental Illness Scale, 22 items (Corrigan et al., 2010)
7. Authenticity Scale, 12 items (Wood et al., 2008)

Negative:
1. Self-Stigma in Mental Illness Scale, 20-item brief version (Corrigan et al., 2012)
2. Shame about having a mental illness, 1 item ('Do you feel ashamed about having a mental illness?'; from 1, not at all, to 7, very much)
3. Social withdrawal and secrecy, 17 items (Link et al., 2002)
4. Cognitive appraisal of stigma as a stressor, 8 items (Rüsch et al., 2009b;Rüsch et al., 2009a)
5. Barriers to Care Evaluation Scale, 30 items (Clement et al., 2012)
6. Attitudes to Disclosure Questionnaire, 28 items (Rüsch & Corrigan, unpublished)

Measured at baseline (t0), three weeks after baseline (t1) and six weeks after baseline (t2)

### Overall study start date
01/11/2012

### Completion date
01/05/2013

## Eligibility

### Key inclusion criteria
1. At least one self-reported current axis I or axis II disorder according to Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) (American Psychiatric Association, 1994), which is not restricted to only substance-related disorder(s)
2. Age 18 or above, male and female
3. Ability to provide written informed consent
4. Fluent in German (for self-report measures)
5. At least a moderate level of self-reported disclosure-related distress/difficulty (score 4 or higher on the screening item 'In general, how distressed or worried are you in terms of secrecy or disclosure of your mental illness to others?', rated from 1, not at all, to 7, very much)

### Participant type(s)
Patient

### Age group
Adult

### Lower age limit
18 Years

### Sex
Both

### Target number of participants

### Key exclusion criteria
1. Self-reported diagnosis of only a substance- or alcohol-related disorder, without non-substance related current psychiatric comorbidity. We will exclude people who only have a substance-/alcohol-related disorder because the disclosure of these disorders is not the topic of this intervention.
2. Intellectual disability
3. Dementia or other organic disorder
4. Current psychiatric inpatient treatment

### Date of first enrolment
01/11/2012

### Date of final enrolment
01/04/2013

## Locations

### Countries of recruitment
Switzerland

### Study participating centre
**Psychiatric University Hospital Zürich**
Zürich
Switzerland
8004

## Sponsor information

### Organisation
Psychiatric University Hospital Zürich (Switzerland)

### Sponsor details
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### Sponsor type
Hospital/treatment centre

### Website

http://www.en.usz.ch

# Funder(s)

**Funder type**
Hospital/treatment centre

**Funder Name**
Psychiatric University Hospital Zürich (Switzerland)

**Funder Name**
Sanatorium Kilchberg (Switzerland)

**Funder Name**
Illinois Institute of Technology, Chicago (USA)

# Results and Publications

**Publication and dissemination plan**
Not provided at time of registration

**Intention to publish date**

**Individual participant data (IPD) sharing plan**

**IPD sharing plan summary**
Not provided at time of registration

**Study outputs**

| Output type | Details | Date created | Date added | Peer reviewed? | Patient-facing? |
|---|---|---|---|---|---|
| Results article | results | 01/06/2014 | | Yes | No |