Efficacy of self-stigma treatment programs: Insights based on a systematic review of the literature

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Social stigma

Individuals are stigmatized when they possess, or are thought to possess, an attribute or characteristic that conveys a social identity that is devalued in a particular society (Crocker & Major, 1989)

North America & Western Europe :

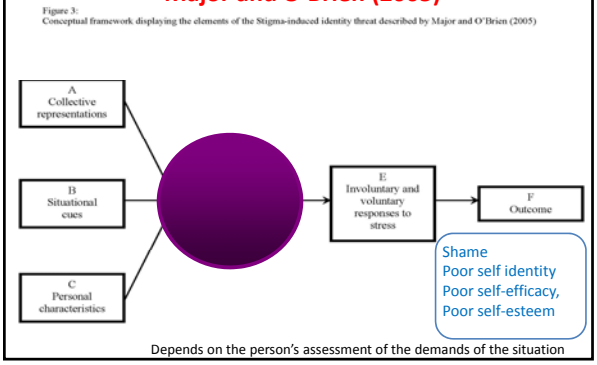
HL is associated with:

- reduced intellect (Doggett, Stein, & Gans, 1998)
- undesirable (maladaptive) behaviors (Erler & Garstecki, 2002; Jones, 1984)
- aging (Oyer & Oyer, 1985; Wallhagen, 2010)

Self-stigma

- Stigmatized individuals are aware of the negative stereotypes directed towards them and they are conscious that they may be devalued by others (Goffman, 1963).
- **Some people agree (consciously or not) with the negative stereotypes and prejudicial attitudes associated with their stigmatizing condition**
- Self-stigma serves as a threat to ones self-efficacy, self-esteem, pride, and self-identity, etc… (Crocker & Major, 1989; Major & O'Brien, 2005; Steele, Spencer, & Aronson, 2002).

Conceptual framework of self-stigma described by Major and O'Brien (2005)



Obstacle to treatment

Self-stigma can be an obstacle to seeking treatment and/or to maintain a prescribe treatment regimen

Especially true if the health condition is not readily visible to others (e.g. HL, mental health, depression, incontinence)

Self-stigma due to HL:

Deny/minimize problems

Postpone consulting professional (avoid/delay threat to devalued identity)

Choose not to use hearing aids (marker of disability, old age, etc..)

Goal of review

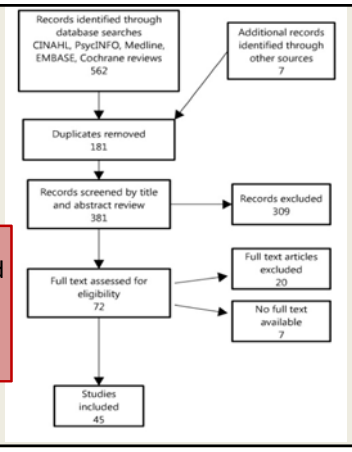
Systematic evidence-based review of the literature to:

- Determine whether efficacious self-stigma reduction programs exist
- Explore whether aspects of those programs might be applied to older adults who self-stigmatize about their incontinence (and also HL)

*For the review, all stigmatizing traits were considered

For the quantitative studies:
N=45

For the qualitative/mixed studies:
11 -2 excluded = 9 studies



General characteristics of the quantitative studies

Data analysed under three main themes

1. Type of intervention program / focus for action
2. Duration of intervention programs
3. Modality of intervention programs

Type (focus) of intervention

Three main typologies (not mutually exclusive) were identified:

A. Focus on developing adaptive skills

e.g.: Psychoeducation; CBT; Acceptance-based Cognitive Therapy; single counseling session, on line discussion group; participatory action research, creative expression

Type (focus) of intervention

Three main typologies (not mutually exclusive) were identified:

B. Focus on creative expression

e.g.: photovoice, writing (novella), decoration of waiting room)

Type (focus) of intervention

Three main typologies (not mutually exclusive) were identified:

C Focus on changing public perspective

e.g.: psycho education; public lectures including stigmatized individuals and their SO

Duration of intervention programs

- Single-session;
- Short-medium term programs (2 – 9 sessions);
- Long-term duration (10 or more sessions)
- Not specified

Modality of intervention

- Individual sessions vs. group sessions
- Professionally led vs. Peer led vs. both professionally and peer led;
- Professionally led, single session;
- Professionally or peer led interventions with no interaction
- Professionally or peer led community interventions with social interaction

Summary of main findings (what seems to work)

1. Psychoeducation based intervention programs that are professionally led and provided in a group format
2. Provide information about the stigmatized health condition
3. Provide contact with other individuals living with the same health condition

Summary of main findings (what seems to work)

4. Intervention programs that focus on self-disclosure
5. Self-help groups

Analysis of qualitative studies

General characteristics of the qualitative studies

11 countries

Health conditions:

- HIV-AIDS (n=4)
- Leprosy (n=1)
- Depression and severe mental illness (i.e., schizophrenia or long-enduring major depressive episodes) (n=2)
- Fat acceptance (n=1)
- Substance abuse (n=1)

Characteristics of treatment program

Cognitive Behavioral Therapy (n=2)

Psychoeducation (n=5)

Creative expression activities (n=2)

Procedures used to collect the data

Focus groups (n=4)

Individual interviews (n=6)

Field notes by investigators (n=1)

Participatory observation (n=1)

Analysis procedure

- listing of all the outcomes reported
- outcomes listed were grouped into categories based on their similarity
- thematic analysis of the major findings

Results

Observation

Successful self-stigma treatment programs can bring about changes at three different levels:

- Emotional
- Cognitive
- Behavioral

Emotional level

Three studies

(Dickins et al., 2011; Laegsgaard et al., 2010; Roe et al., 2010)

Participants reported positive changes in emotional state related to feelings of:

- Shame
- Guilt
- Hopelessness

Emotional level

Laegsgaard et al. (2010): Depression

- People with depression might blame themselves for having this health condition
- Common stereotype: people do not have the willpower to pull themselves together; it is their fault if they are depressed
- This self-blame may lead to a diminished self-identity and feelings shame and guilt

Emotional level

Laegsgaard et al. (2010): Depression

Treatment:

Genetic counseling and genetic analyses of persons with family history of depression

Emotional level

Laegsgaard et al. (2010): Depression

Results:

- genetic analyses helped the individuals externalize the origin of their health condition
- depression was seen as being caused by a genetic disorder rather than a weakness in the individual's coping skills
- Consequence:
  less shame & guilt about their health condition

Cognitive level

- the self-stigma reduction program led participants to ***reinterpret their health condition in such a way that it facilitated its acceptance***

Cognitive level

Laegsgaard et al. (2010): Depression; genetic factors

knowing the origin of the disease helped reinterpret the family history of the mental health condition

The treatment:

made it possible for the participants to re-evaluate past experiences which enabled them to accept their health condition

Dickins et al., 2001

Fatosphere Blog

Persons who perceived themselves as having a weight problem

Participation in a world-wide blog

Emotional level

Dickins et al., 2011: Fatosphere Blog

Before treatment

- participants felt responsible for their weight problem
- believed that the only way of overcoming that social stigma was by becoming thin

After treatment (Blog)

- participants used fat acceptance rather than weight loss as means to deal with social stigma

Dickins et al., 2011: Fatosphere Blog

Emotional level

As a result of participating in the blog, a reduction in the shame and guilt they experienced due to their weight

or more specifically due to the prejudicial attitudes of friends, family members and health professionals concerning their weight

Dickins et al., 2011: Fatosphere Blog

Cognitive level

Results

- some participants came to challenge societal norms regarding fatness and obesity
- they ignored the medical discourse that encouraged weight loss which led the participants to adopt healthy behaviors

Dickins et al., 2011: Fatosphere Blog

Cognitive level

- Participants reported developing a more balanced relationship with food, overcame eating disorders, and felt more comfortable engaging in physical activities.
- For many participants, accepting their health condition was the significant factor that brought about a change in their behaviors

Behavioral level

Successful participation in a self-stigma treatment program may lead to changes in behavior such as:

- disclosing one's health condition to others
- accepting to engage in a help seeking process
- adhere to a treatment regimen

Behavioral level

Disclosing one's stigmatizing condition to others can be difficult because one risks being stereotyped and devalued

Disclosure exposes one's vulnerabilities and places people at risk of experiencing social stigma

Disclosure may also result in benefits such as gaining a sense of 'relief' (not having to hide a condition or having to keep it a secret)

Behavioral level

Roe et al. (2010) – Mental illness

- After CBT treatment program participants reported an increase in their willingness to disclose their health condition.
- This resulted in a reduction in self-stigma (not having to keep the secret)

Behavioral level

Gibbs and Rae Olmstead (2011) Substance abuse

- soldiers were permitted to register in the treatment program without referral from a superior
- to ensure confidentiality, treatment sessions were held separately for officers and non-commissioned officers
- meetings were held outside of duty hours

Behavioral level

Gibbs and Rae Olmstead (2011) Substance abuse

Results:

- participants reported feeling more in control related to, if, when, and to whom they disclosed their health condition.
- Many participants did end up disclosing to superiors and peers (but on their on terms!)

Table 2. Level at which positive outcomes were observed

Authors, year	Health Condition	Data collection technique	Level at which positive outcomes were observed
Arole et al. (2002)	Leprosy	Focus groups	Cognitive level Behavioral level
Dickins et al. (2011)	Fatness	Individual semi-structured interviews (via telephone or Skype)	Emotional level Cognitive level Behavioral level
Gibbs and Rae Olmsted (2011)	Alcohol abuse	Focus groups	Behavioral level
Laegsgaard et al. (2010)	Depression	Focus groups	Emotional level Cognitive level Behavioral level

Table 2. Level at which positive outcomes were observed

Authors, year	Health Condition	Data collection technique	Level at which positive outcomes were observed
Neema et al. (2012)	HIV/AIDS	Key informants and focus group discussions	Emotional level Cognitive level Behavioral level
Nguyen et al. (2009)	HIV-AIDS	Individual interviews	Behavioral level
Rao et al. (2012)	HIV-AIDS	Group discussion; Written answers to open ended questions	Emotional level Cognitive level Behavioral level
Roe et al. (2010)	Severe mental illness	Semi-structured interviews	Emotional level Behavioral level
Skinta et al. (2014b)	HIV-AIDS	Individual post-treatment interviews	Emotional level Cognitive level

Discussion and conclusions

Advantages of using qualitative approaches

- the effects of the treatment program are not limited to analyzing the results of outcome measures selected before the study started
- results can be reported in whatever domains observed by the investigators and/or reported by the participants themselves

Discussion and conclusions

Some self-stigma treatment programs are efficacious

the results of all 9 qualitative studies retained for the present review revealed that the self-stigma treatment program under investigation was beneficial to participants,

at least to some extent (i.e., some participants noted positive improvements)

Discussion and conclusions

Changes at:

- **Emotional level** (less shame , guilt, hopelessness)
- **Cognitive level** (re-interprete/analyse their health condition in a more favorable manner
- **Behavioral level** (disclosing and treatment adherence)

Discussion and conclusions

Review provided insights into the type of outcome measures that may be used when planning quantitative self-stigma treatment program:

- A function of the target of treatment program: emotions, cognitive, behavior
- Need homogeneous group of participants re: where they are on the 'self-stigma journey'

Thank you

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