

The role of self stigma and insight in the recovery process: The theoretical rationale for NECT

David Roe, Ph.D

Professor

Department of Community Mental Health

Faculty of Social Welfare and Health Sciences

University of Haifa, Israel

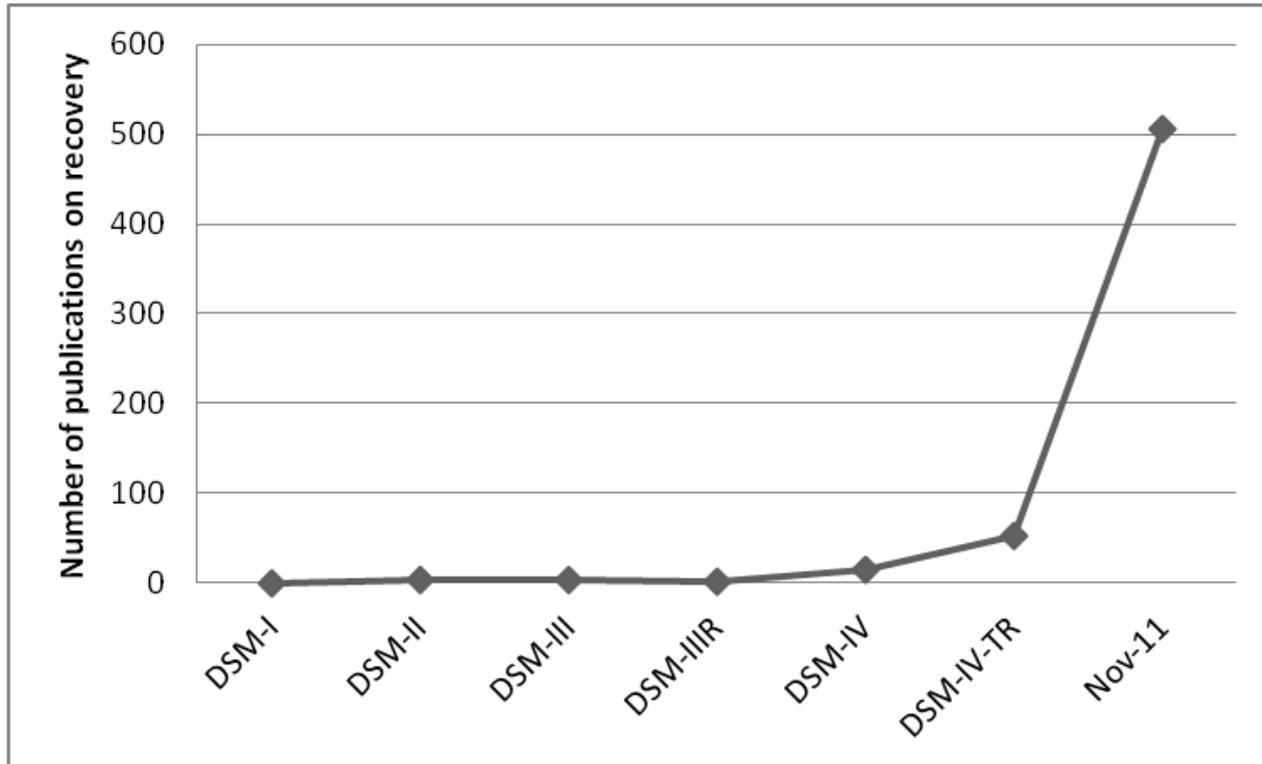
droe@univ.haifa.ac.il

Special Thanks To:

Research Partners: Paul Lysaker (Roudebush VA, Indiana-Purdue University), Phil Yanos (CUNY), NIMH-funding (R34MH082161)

Recovery

Pubmed articles on “Recovery”



Zisman-Ilani, Y., Roe, D., Flanagan, E. H., Rudnick, A. R., & Davidson, L. (2012). Psychiatric diagnosis: what the recovery movement can offer the DSM-5 revision process.

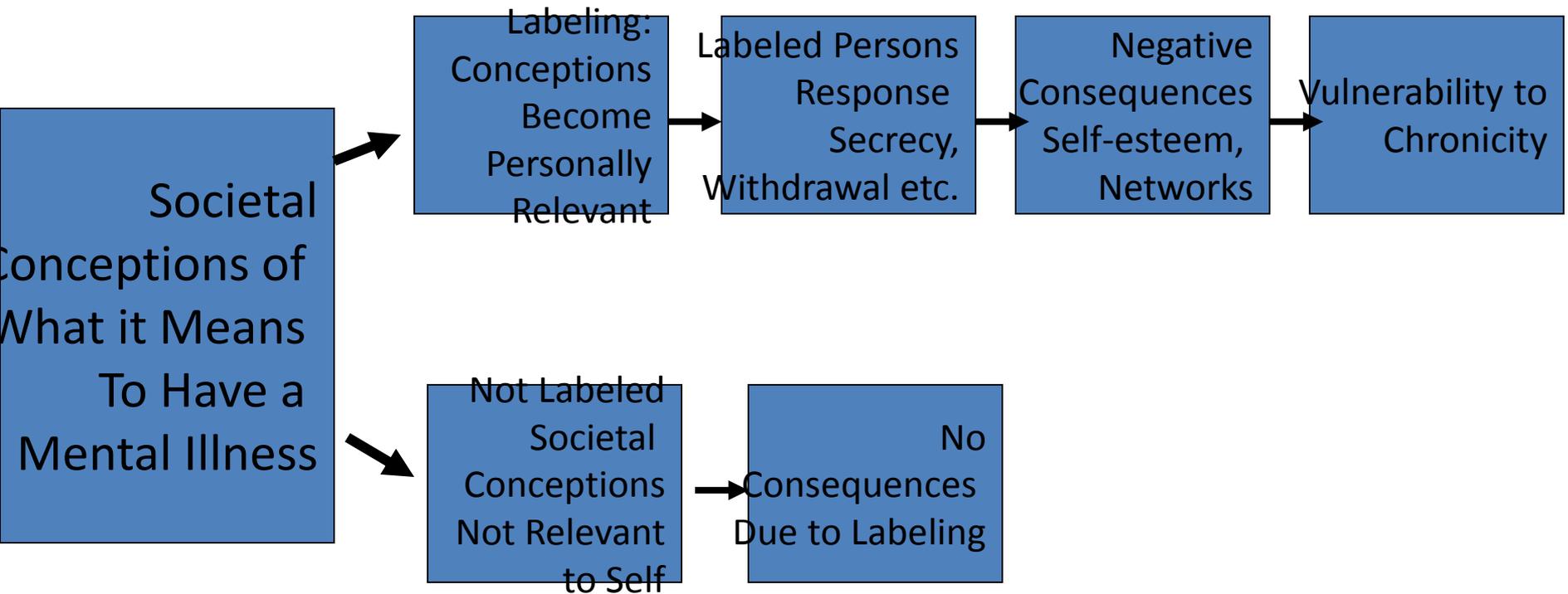
Stigma as a barrier to recovery

The Stigma Concept

Stigma exists when the following interrelated components converge:

1. people distinguish and label human differences
2. labeled persons are linked to undesirable characteristics -- to unwarranted negative stereotypes
3. labeled persons are viewed as an outgroup as “them” and not “us”
4. people experience emotional reactions to labeled people – fear, repulsion, disgust and labeled persons may feel shame, embarrassment, humiliation
5. labeled persons experience status loss and discrimination as a consequence
6. stigma is dependent on power

Modified Labeling Approach



From Stigma... to Self-Stigma

Awareness of Stereotype

Agreeing with stereotype

Stereotype endorsement

How Commonly Do People Develop Self-Stigmatized Identities?

- Roughly a third of people with SMI develop high levels of self stigma
- (Brohan et al. 2010; Ritsher & Phelan, 2004 ; West et al., 2011)

Meta-Analysis of Impact of Self-Stigma

Livingston & Boyd (2010) conducted a meta-analysis of 127 studies examining consequences of self-stigma

Significant effects were found for hope (-.58), self-esteem (-.55), self-efficacy (-.54), quality of life (-.7), and social support (-.28) AND treatment adherence (-.38)

Sociological Theories

Goffman (1961) describes the “contribution” of the institutionalization process through “stripping” one from his or her identity

Scheff (1966) “unwanted”, “deviant behavior” influencing labeling

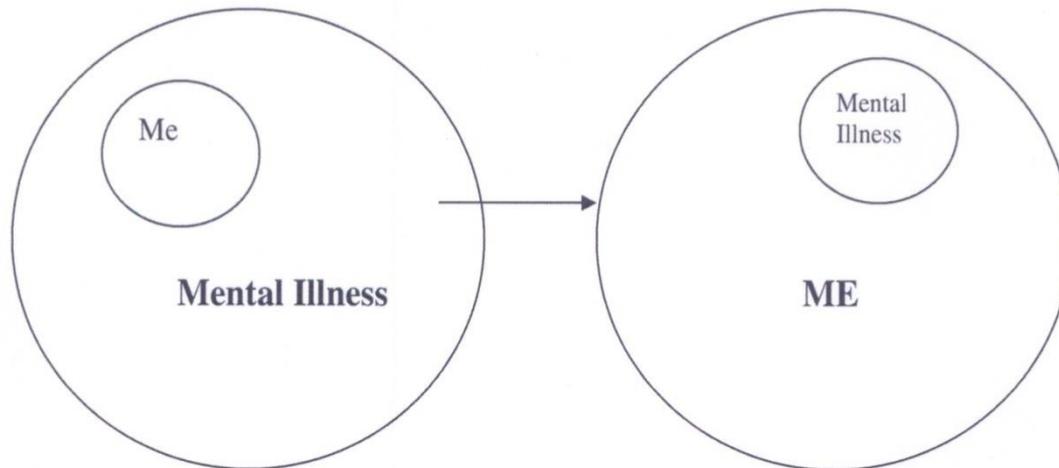
Thoits (1985) restricting valued social roles

Estroff (1989)- “I am illness”

Lally (1989) – Role engulfment

Identity and recovery

The Recovery Journey



From experience of self to
experience of illness: the concept of
insight

- Insight has been found to be associated with both positive outcomes (better functioning) and negative outcomes (greater depression/hopeless)

Lack of insight an item PANSS

G12. LACK OF JUDGEMENT AND INSIGHT - Impaired awareness or understanding of one's own psychiatric condition and life situation. • This is evidenced by failure to recognise past or present psychiatric illness or symptoms, denial of need for psychiatric hospitalisation or treatment, decisions characterised by poor anticipation or consequences, and unrealistic short-term and long-range planning. Basis for rating – Thought content expressed during the interview. 1 Absent - Definition does not apply 2 Minimal - Questionable pathology; may be at the upper extreme of normal limits 3 Mild - Recognises having a psychiatric disorder but clearly underestimates its seriousness, the implications for treatment, or the importance of taking measures to avoid relapse. Future planning may be poorly conceived. 4 Moderate - Patient shows only a vague or shallow recognition of illness.

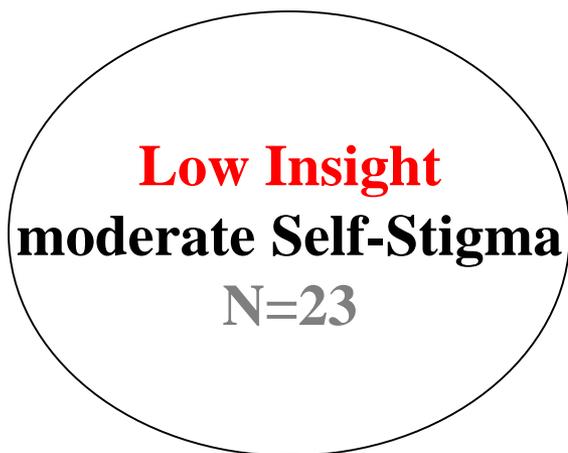
Some of our work on the topic

Does self-stigma moderate the impact of insight?

self-stigma moderate the impact of insight on functioning, social relationships and hope

Lysaker, Roe, & Yanos (2007)

Cluster analysis of insight and self-stigma levels of 75 people living with schizophrenia led to 3 clusters/groups



Study 1 Take Home Message

- “Advantage” of insight is lost when it is combined with self-stigma
- People with high insight and high self-stigma have greater symptoms, less hope, lower self-esteem, and worse social relationships than both people with high insight/low self-stigma, and people with low insight/low self-stigma

Beyond descriptive insight

(Roe et al, 2008)

- 65 persons with schizophrenia spectrum disorders
- Themes of narratives of insight were identified and rated independently by 2 raters
- We tested if traditional insight scores differentiated between the profiles

Rejects Illness/Searches for Name (n=9)

Do not believe that they had an illness but are searching for an explanation of title for their condition:

Interviewer: Do you think you have a mental illness?

Subject: No.

Interviewer: Have you ever had a mental illness?

Subject: No.

Interviewer: Have you ever experienced anything, or has anybody talked with you about having one?

Subject: Yes. When I first . . . I used to hear voices, and I still hear them sometimes, but I don't pay any attention to them . . . I believe that I'm controlled by a demon. Otherwise I wouldn't have done all these bad things.

Accepts Illness/Rejects Label (n 9)

Admitted both to having an illness and to having symptoms but rejected the terms used officially to characterize their illness and symptoms.

Interviewer: do you think you have a mental illness?

Participant: Yeah, I uh, I haven't heard any voices lately, and I have hallucinations; I see little things running around on the floor. I mean, I knew it wasn't right. (Laughs). Sometimes I can hear breathing other than my own. I don't know what that is, call it a monster for lack of anything else.

Passive Acceptance

(*n* = 18)

Believed they had a mental illness and accepted the diagnostic label but rejected having had symptoms and were not searching for a name or explanation.

Interviewer: Do you think you have a mental illness?

Subject: Yes, I know I have an illness.

Interviewer: What do you think it is?

Subject: Manic depressive.

Interviewer: What does that mean, what are the symptoms?

Subject: I don't know they told me many times

Integrative Insight

(n 29)

Believed they had an illness, identified its symptoms, and accepted the label. However, they also remained curious about it and active in understanding it.

It's labeled schizoaffective, and what happens is I have audio and visual hallucinations. Um, I draw erroneous conclusions to some of these audio and visual hallucinations that I have. I've even felt like I was being beaten when there was no one there to do the beating. Uh . . . I have had strange thoughts about being attacked by spirits from the spirit world, and I've had a difficult time living with the thoughts and the experiences that I have had.

Take home message of study

- There are different ways to be aware of an illness
- Meaning making processes may be important

NECT

Narrative Enhancement Cognitive
Therapy

Development of NECT

- We developed Narrative Enhancement and Cognitive Therapy (NECT) in 2006-2008
- 20 session manualized group intervention
- Consists of 3 elements:
 - Psychoeducation
 - Cognitive restructuring
 - Narrative enhancement

Section 1: getting started

Exploring self and illness and how they relate •

Section 2: Psychoeducation

- Present and discuss common myths and challenge these with facts.
- Discuss the dilemma regarding disclosure

Getting started: Exploring self, illness and self in relation to illness

Exercise 1: Take a few minutes to describe yourself as you are at this point in your life.

Conveys message: primary interest is in YOU as a PERSON and your right and our faith in your ability to DESCRIBE YOUR SELF cause YOU ARE THE EXPERT of who you are and we are interested to learn about you FROM you.

- ***Exercise 2: Take a few minutes and describe your thoughts and feelings about any experiences you have had with mental illness and psychiatric treatment.***
- *Again, the message is = this is your life and your story of which you are the expert and we are inviting you to explore and are curious to be an audience and facilitator of this process.*
- *Also – we do not care if you believe you have a mental illness or not and are not getting in to this at all but rather are inviting you to share your experiences you may have had with this broad issue*

*Exercise 3: describe how the illness
you have been diagnosed with relates to YOU*

- 1) Encourage the person to use their ability to “think about thinking” to zoom out a little and reflect upon the possible mutual influences between him/her and the issue with which dealing (what ever they call it).
- 2) The “recovery journey” figure on page 10 can help make some of the somewhat abstract concepts more concrete and tangible so that the person can connect almost on a visual level on what the purpose of NECT is about.

Narrative Enhancement and Cognitive Therapy: Psychoeducation Section

- The purpose of psychoeducation is to present and discuss common myths about people with mental illness and challenge these with facts.
- Another goal is to discuss the dilemma regarding disclosure (whether or not to share with others the diagnosis of mental illness)

Narrative Enhancement and Cognitive Therapy: Psychoed section

- 1) The section begins with a more detailed description of stigma and self-stigma
- 2) Participants are encouraged to share personal experiences so that discussion is not only abstract and theoretical
- 3) Constantly stress that self-stigma is a social construction resulting from social stigma – it is NOT part of the illness or the persons' fault!

Four common myths are presented and challenged by facts

Myth # 1: People with mental illness tend to be violent. •

Myth #2: People with mental illness cannot work. •

Myth #3: People never recover from mental illness •

Myth #4: People diagnosed with a mental illness are always out of touch with reality. •

Disclosure: There is no clear answer about whether to disclose or not to disclose; it is a personal issue” (Corrigan and Lundin, 2001)

- Stigma and self stigma often lead to a desire to conceal having a mental illness
- An invitation to explore the pros and cons of concealing and sharing, when and with whom is NOT necessarily a call for action!
- Clearly both concealing and sharing have their pros and cons which need to be considered

Section 3: Cognitive Restructuring

Narrative Enhancement and Cognitive Therapy: Cognitive Restructuring Section

The section proceeds in 4 stages: •

1) teaching the connection between thoughts and feelings

2) teaching the connection between thoughts, feelings, and behavior

3) teaching how stigma and self-stigma impact thoughts, feelings and behavior

4) teaching strategies for thinking differently when confronting negative thoughts

- 3 different approaches are offered for examining and replacing negative thoughts:
- “*Be a scientist*” (essentially traditional CR of examining evidence),
- “*Take your own advice*” (focuses on taking a different perspective on the situation)
- “*No judgment zone*” (focuses on the judgmental nature of the words that are used in the thought)
- self-talk statements

Section 4: Narrative Enhancement

- Engages participants in the process of telling and retelling stories about self to:
- Convey message of entitlement to story
- Form a context to experience the benefits of constructing a story (universal, accessible, encourages meaning making, facilitates continuity, is flexible and “owned” by the person
- .

Narrative Enhancement and Cognitive Therapy: Narrative Enhancement Section

The section proceeds in 4 stages:

- 1) Introducing participants to the rationale for the coming story-telling exercises
- 2) Reviewing “tips on storytelling” (which guides participants on ways to tell stories that are relevant for the group) and “guide to giving feedback on stories” (which gives guidance on how to give appropriate feedback on other participants’ stories)
- 3) General and specific (exercises calling for specific types of stories) story-telling exercises
- 4) Wrapping-up (a repetition of the initial stories about themselves that participants wrote in the orientation sessions)

NECT: Research Status

- NECT has been studied in one medium quasi-experimental study (n = 119) and one small RCT (n = 39)
- A large RCT is currently underway in the US (target n = 175)
- Sweden (!) pilot data hopefully in press and RCT in progress

Narrative Enhancement and Cognitive Therapy: Preliminary Findings from Quasi-Experimental Study in Israel (Roe et al., 2014)

Variable	NECT Time 1 M (SD) N= 63	NECT Time 2 M (SD) N= 63	TAU Time 1 M (SD) N= 56	TAU Time 2 M (SD) N= 56	F (Time x Group)	P	Cohen 's D
ISMI – Total (0-3)	1.08 (0.55)	.85 (0.49)	1.09 (0.54)	1.08 (0.57)	7.81	<.01	0.51
Subjective Quality of Life (QOL) (1-7)	4.51 (1.11)	4.73 (0.92)	4.44 (1.13)	4.32 (1.01)	4.20	<.05	0.38
Hope-Total Scale (1-8)	5.83 (1.42)	6.22 (1.16)	5.70 (1.30)	5.80 (1.43)	1.74	ns	0.25
Hope-Pathway	6.03 (1.35)	6.19 (1.26)	5.79 (1.36)	5.92 (1.49)	0.02	ns	0.03
Hope-Agency	5.63 (1.67)	6.25 (1.29)	5.61 (1.63)	5.68 (1.70)	4.19	<.05	0.38
Self-Esteem (1-4)	2.98 (0.59)	3.20 (0.51)	2.96 (0.57)	2.95 (0.49)	9.37	<.01	0.56

Narrative Enhancement and Cognitive Therapy: Qualitative Findings

- Qualitative analysis with 18 NECT completers in Israel (Roe et al., 2010) revealed six domains of improvement which participants attributed to participating in the intervention: *Experiential learning, positive change in experience of self, acquiring cognitive skills, enhanced hope, coping, and emotional change.*
- Identified processes contributing to positive change included the therapeutic alliance and participants' active role

Narrative Enhancement and Cognitive Therapy: Preliminary RCT Findings

- We conducted a small RCT of NECT with 39 mental health consumers in New York and Indiana (Yanos et al., 2012)
- In addition to the small sample size, significant dropout from the control group was an issue
- Nevertheless, we observed non-significant trends in improvement in the stereotype endorsement subscale of the ISMI and in insight

Conclusions Regarding NECT

- NECT is a promising approach for addressing the impact of self-stigma on the identities of people diagnosed with severe mental illness
- There are encouraging research findings regarding its effectiveness and there have been enthusiastic reactions from clinicians and service-users