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## Literature review of the relationship between illness identity and recovery outcomes among adults with severe mental illness

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**Abstract**

This paper is a literature review of the relationship between illness identity and recovery outcomes among adults with severe mental illness. First, illness identity is explored as presented in the literature, through analysis of work on narrativization, labeling theory and the role of gender stereotypes. Literature on stigmatization as a mediating factor that influences the ways illness identity impacts recovery is also studied. Finally, work is presented on recovery outcomes that are a direct result of self-perception. Findings suggest the existence of two paradigms; positive and negative illness identity as the result of mediating factors from the diagnosis stage. A rough model of the process of recovery vis-a-vis illness identity is, therefore, suggested and the implications of discoveries of the current literature on clinical practice are outlined.

*Keywords:* illness identity, recovery, severe mental illness

## **Literature Review of the Relationship between Illness Identity and Recovery Outcomes among Adults with Severe Mental Illness**

With increasing rates of mental illness diagnosis, and a subsequent increase in suicide cases (Naghavi, 2016) or poor recovery outcomes, there is an ever-growing need to better understand the ways in which the mental health system as a whole caters to, or hinders, the recovery of patients and sets parameters for their recovery environment. One of the ways in which these parameters are set that is often overlooked is in the very definition/ diagnosis of the mental illness with which a patient is identified. For example, people with severe mental illness such as schizophrenia experience stigmatization, either due to negative media portrayal or familial shame, leading to higher risk of suicidal ideation, which is a hindrance to recovery (Pompili, Mancinelli, & Tatarelli, 2003) This inevitably has underlying connotations that are heavily linked to the patient's cultural understanding of mental illness and its consequences (Lefley, 1990), as well as the optimistic or pessimistic outlook they have of the outcomes of their diagnosis(es). An extensive review of literature reveals that the formation of this outlook begins from the stage of diagnosis; however, this process and its effects on recovery are not fully examined. This review hypothesizes that the compounded effects of the narratives patients have about their experiences, the labels placed on them, their gender expression and expectations, and their experiences of stigma may all determine what their relationship to their illness will be. A positive relationship results in better recovery outcomes. Conversely, a negative relationship results in poor recovery outcomes.

An interesting phenomenon was observed in a study that found that rats identified as having a pessimistic outlook through the Ambiguous-Cue Interpretation (ACI) tests were more likely to exhibit anhedonia faster and for longer periods when

exposed to stress factors, compared to rats that were identified as having an optimistic outlook, (Rygula, Papciak, & Popik, 2013). The researchers tested 32 male Sprague-Drawley rats with 10 consecutive ACI tests at one-week intervals (all tests of significance were performed at  $\alpha=0.05$ ). This study proved a link between cognitive judgment bias and risk of depression in rats. In other words, by analyzing the ways the rat subjects created their own subjective realities, through their optimistic or pessimistic outlook, researchers were able to determine if the rats would fare well or poorly in appetitive and consummatory tasks. Generally, rats with a pessimistic outlook were unable to sustain a healthy appetite once exposed to stress factors. Moreover, the researchers concluded, "cognitive bias screening could be used to evaluate the individual differences in response to the therapeutic effects of antidepressant drugs." (Rygula et al., 2013, p. 2195). This evidence predicts that, within a human population, a negative outlook on life outcomes based on one's diagnosis with a severe mental illness leads to the same hindrance to self-regulation when confronted with everyday stressors, but on a more complex scale.

Illness identity is defined as "the set of roles and attitudes that people have developed about themselves in relation to their understanding of mental illness" (Yanos, Deluca, Roe, & Lysaker, 2010, p.74). It has long been termed "engulfment", especially evident in studies of the impact of psychosis and schizophrenia on self-concept (Vining & Robinson, 2016), and is a well-documented phenomenon. However, the literature shows gaps when the impacts of this phenomenon on recovery outcomes are investigated. It is, therefore, necessary and important to understand the link between the two to arrest and mitigate the possible internalization of a negative self-concept based on stigmatizing beliefs about one's diagnosis, which may hinder recovery.

While there is evidence that illness identity extends to all forms of chronic illness (Oris et al., 2018) and evidence that severe mental illness is often classified as a chronic illness, this paper assumes that due to the nature of change available to the state of mental illness (Craig & Hyatt, 1978) and due to the focus of the current literature on engulfment specific to schizophrenia and psychosis, there is a need to study illness identity within the broader category of severe mental illness.

The idea of identity as central to the process of recovery is further explored when recovery is itself conceptualized. A review of literature indicates that "recovery" is a unique and active process that is strongly identified with awareness of "dimensions of identity", "rebuilding/ redefining positive sense of identity" and "overcoming stigma" (Leamy, Bird, Boutillier, Williams, & Slade, 2011). Moreover, recovery itself may become a form of identity, known as "recovery identity", which is difficult to depart from, once established (Howard, 2006).

In addition, models of labeling theory, as well as classic stigmatization theories (Link & Phelan, 2001; Goffman, 1990) provide evidence for the role played by society and grouping in the maintenance or reinforcement of illness identity (Pasman, 2011). Therefore, it is important to investigate the function that societal beliefs and social psychology serve in the relationship between illness identity and recovery outcomes. Moreover, identity negotiation theory indicates the importance of society in determining the development and acceptance of identity (Ting-Toomey, 2017). Essentially, this theory suggests that individuals arrive at their identity by first investigating and establishing the roles and positions of others in society and then comparing these positions relative to their own.

This paper seeks to analyze the relationship that exists between the established concepts of illness identity and recovery outcomes. Focus will be placed on

stigmatization as a factor in the formation of illness identity, which impacts recovery. However, this paper also seeks to outline the positive impacts that may come as a result of group identification once a patient has a diagnosis or label with which they can identify other individuals who share their experiences

In writing this review, databases used to search for articles included: PsycINFO, Research Gate, the BMJ (British Journal of Medicine) website, JSTOR, ProQuest Research, PsycARTICLES, SAGE Research Methods Online, APA's PsycNET, ScienceDirect and Cambridge Core. The search terms used included: 'illness identity' OR 'Severe Mental illness' OR 'engulfment' OR 'psych\$' AND 'recovery outcomes' OR 'stigma' OR 'self-stigma' OR 'labeling theory'. Based on the information within the resulting abstracts and the references provided within these articles, further articles were obtained. Literature that referred to chronic illness on a broad scale, or was primarily about adolescents or children was excluded.

### **Formation of Illness Identity from the Diagnosis Stage**

Diagnosis of severe mental illness provides a patient with a new "label", about which they have previously held notions and associations that inform their identity after diagnosis. This process is explained in the literature in three key ways: narrativization, labeling theory, and gendered differences in the experience of diagnosis with a mental disorder.

#### **Narrativization**

Narrativization can be described as the process through which individuals makes sense of their lived experiences by interpreting them as a linear sequence of events which compound to form a single story or narrative. In his work, Baldwin (2005) provides clarity in the ways narrative is an essential part of the creation of

identity, specifically identity with regards to being diagnosed with a mental illness. Key concepts that can be extracted from his work are discussed here. First is the idea that narrative is essential to the creation of self-concept. However, within the realm of mental illness, a profundity arises: while the patient requires narrative to maintain a sense of self which would allow a faster return to the status quo ante and "normality", the same patient must face a loss of their ability to maintain narrative integrity, since patients with severe mental illness are often incoherent, and narrative agency, since their state leaves the patient dependent on others to narrate their life and unable to do so themselves.

Baldwin further presents an interesting idea, that loss of the ability to create and maintain narratives that inform our identity is not only a function of the illness itself, but also due to societal conceptualization of narrativization itself; that is, society generally does not create spaces for mentally ill individuals to narrativize their lives, but rather depends on default imagery and narratives from the collective consciousness that ascribe set traits to the mentally ill. Therefore, the individual diagnosed with severe mental illness is not only unable to define their own identity, but also has this identity prescribed to them by a society with set notions.

Baldwin, however, limits his findings to the interaction of society with the individual labeled as mentally ill. When it comes to the interaction of the clinician with the patient, Roberts (2000) provides insightful material. Essentially, Roberts views narrative not only as a part of the process of identity formation for the individual, but also as central to the therapeutic process. Where traditional approaches fixate on evidence-based medicine, Roberts proposes the need to consider narrative as a tool to better understand the patient's experience, as well as maintain their "individuality", "distinctiveness" and "context". Essentially it allows the patient to

feel less a part of a generalized grouping, due to their diagnosis, and more like an individual with a unique challenge to surmount. Roberts places the onus of narrativization on the clinician, who must understand the recovery outcomes that are important to the patient and guide the recovery process with these in mind. Moreover, Roberts' work claims "chronicity may partly arise from our accumulated negative expectations" (p. 438), a nod to the notion that negative discourse surrounding a patient's "label" leads to a cycle of behavior that is retrogressive to the recovery process due to the integration of hopelessness into the patient's identity. Finally, Roberts indicates the need to create new narratives to facilitate recovery:

...recovery involves the restoration of hope, agency, self-determination and a way of adjusting to living with both the reality of the past and the continuing altered experiences of 'illness'. This very different perspective enables the prospect of recovery to become a realistic goal for every patient, and it is one of the inspirational dynamics of rehabilitation, enabling Clay (1999, cited in Roberts, 2000) to declare, "From the experience of madness I received a wound that changed my life. It enabled me to help others and to know myself" (Roberts, 2000 p. 438)

Baldwin and Roberts, therefore, both provide for the centrality of "story telling" and the discourse of mental illness to the self-conceptualization of the individual diagnosed with severe mental illness. However they differ in their focus; Baldwin focuses on narratives as created by society, while Roberts focuses on narratives created within the clinical environment. Moreover, Roberts indicates the need for balance between symptomatology and narrativization, where the clinician must observe the individual they are treating, not only as a person who requires positive narratives to maintain integrity of self-concept, but also as a patient, first and



foremost, who presents symptoms of a labeled disorder. The two studies, however, fail to indicate where narrativization falls within the process of diagnosis and recovery.

### **Labeling Theory**

Narratives culminate in the creation of "labels" associated with a diagnosis of mental illness. Labeling theory thus emerges as a way of understanding the impact of the use of labeling, or generalized descriptions that differentiate groups of people, as having a tangible effect on the behavior exhibited by that "deviant" group of people.

Berk (2015) aptly describes the history and importance of labeling theory in his work. Evidently, there has been a tangible correlation between suicide and societal organization, indicating the interaction of society, the parameters it creates and its perceptions, with the outcome of severe mental illness. While the earliest indication of this discourse is evidenced in the work of Durkheim in 1897, the theory gained traction in the 60s when researchers such as Scheff and Goffman began to focus on societal reactions (Berk, 2015). Berk indicates that the development of labeling theory has been, in many ways, disorganized. This may be because of generational effects; the importance of the theory has varied with different generational movements that call for attention to be placed on the treatment of marginalized groups, e.g., the freedom movements of the 70s. Alternatively, it may be because of its almost mutually exclusive existence within both the domains of sociology, which focuses on the macro-scale impact of society, e.g., the work of Erving Goffman, and psychology, which focuses on the psychological impact felt by the labeled individual, e.g., the work of Erikson.

In either case, Berk notes a common thread; the idea that:

Moral norms must be studied in action as they are created, invoked, or applied in everyday interaction, and that you can never tell what the norm is until people are actually negatively reacted to by others and this is highly variable (Becker, 1963). It is [others'] reaction to them that makes them deviant, not the act itself. (Berk, 2015, p.151).

Thus, the notion that labeling others as "different from", in fact, leads them to exhibit deviant behavior consistent with their label, i.e., their new illness identity. This phenomenon of deviance as a result of labeling is known as secondary deviance. He further indicates that this idea is solidified in studies of recidivism within the realm of criminology.

Berk's work is of particular interest to this study, where he indicates a palpable difference between "formal" and "informal" labeling within the literature; that is, varied circumstances may have an impact on the effectiveness and duration of labeling effects. Notably, differences in gender, age, and ethnicity may also play a role. Berk indicates that there is a bank of literature that solidifies the impact of labeling on symptom relapse, rehospitalization and stigma of patients diagnosed with severe mental illness (this idea is later expounded). Finally, he posits larger macro concerns that may arise from labeling culture; he notes the idea that, when deviant groups are labeled as such, it is often with the end goal of creating power dynamics within society through the creation of a status that is "less than", as is seen with criminal institutions in America, which serve as something of "a new Jim Crow system" (2015, p.154).

Whereas the literature indicates Scheff (1999) as one of the earliest proponents of the ideas of the original labeling theory, strong criticism comes from the work of Weinstein (1983). Weinstein's work takes on a more positivistic approach,

emphasizing the need for measurable variables and a focus on the patient's own evaluation of their attitudes to mental illness labels. In fact, one distinction he makes between proponents of the theory and critics is that critics view mental illness as a defined set of abnormalities that can be cured within the realm of medicine, similar to Roberts' (2000) indication of the contemporary inclination to EBM, while proponents oversimplify mental illness as a label attached to behavior. He indicates that neither proponents nor rebuttals take the patient's perspective into account; essentially, Scheff's original work focused on residual unorthodox behavior as a definition of psychiatric symptoms, while his contemporary critics focused on the ambiguity inherent in this argument. Moreover, Weinstein indicates, like Berk (2015), that there are discrepancies between sociological and psychological approaches to labeling and these make it difficult to validate the theory and its effects.

Weinstein proposes that a re-examination of the theories that gave rise to the original labeling theory would reveal a paradox: George Mead's original work, which informed early labeling theory, emphasized the phenomenology of the individual, whereas current focus has shifted to society. There is, therefore, a need to approach illness identity through the lens of labeling, with an awareness of the failure of the theory to fully take into account the position of the patient.

Through a review of 35 studies, Weinstein proves that 5 key assumptions made within the original labeling theory are false. These assumptions are:

- Hospitalized patients tend to espouse unfavorable attitudes towards mental illness;
- Patients' attitudes towards mental illness become more unfavorable during the course of hospitalization;

- Patients are less favorable in their attitude towards mental illness than non-patients;
- Ex-patients tend to express unfavorable attitudes toward the stigma of mental hospitalization;
- Ex-patients' attitudes towards the stigma of mental hospitalization, compared to their pre-discharge attitudes, will be more unfavorable (Weinstein, 1983, p.72-73)

Moreover, he argues that original theories assume that patients are exposed to unfavorable clinical environments which would negatively impact their self-concept and that, because original proponents observed their findings through immersive techniques, e.g., impersonating mentally ill individuals to observe/participate in their experiences, they would be intrinsically uncomfortable, leading to negative biases. He concludes by indicating the need for a modified labeling theory.

Link, Cullen, Struening, Shrout, and Dohrenwend (1989) provide such a theory and a counter critique in response to the work of Weinstein and others. Their paper begins by establishing that the opinion that stigma is transitory or has little to no effect on the lived experience of labeled individuals (as stated in critiques of Scheff's work) is over-pessimistic at best. However, they depart from Scheff in their emphasis. Here, their theory focuses on the labeled individual's responses and insists that labeling itself cannot cause mental illness but it can cause negative outcomes which render patients vulnerable to chronicity. Link et al. (1989) arrive at this focus by investigating the experience of 429 community residents and 164 psychiatric patients in Washington Heights, New York. They conducted face-to-face interviews with these participants between 1980 and 1983 and grouped them with distinctions on psychiatric status and labeling exposure.

Link et al. (1989) thus propose 5 steps in the creation and internalization of labels, which for the purposes of this study serve the same function as internalized illness identity: step 1: beliefs about devaluation and discrimination; step 2: official labeling (what Berk (2015) refers to as formal labeling) through treatment contact; step 3: patient's responses to their stigmatizing status (the use of "secrecy", "withdrawal" or "educating others" as tools of coping with their new illness identity); step 4: consequences of the stigma process on the patient's life (discussed later in this paper); and step 5: vulnerability to future disorder (discussed later in this paper) (1989, p.402-4)

Additionally, Link et al. (1989) indicate that the patient's view of mental illness is well established prior to their diagnosis. Principally, jokes, cartoons, and the media's reporting of mental patient status can influence views of what it means to be mentally ill. Drawing on sources like these, all members of society - those who will become psychiatric patients as well as those who will not - form conceptions of what it means to acquire that status. (p.402).

Therefore, the internalization of the status of "mentally ill" that occurs in stage 2 and the beliefs this generates about implications of the label affect social connectedness. The illness identity formed has a tangible effect on the patient's life, even post-diagnosis.

Where Weinstein argues that the attitudes of the public and the patient are "too positive to make labeling theory believable" (Link et al., 1989, p. 420) Link et al. argue that critics such as Weinstein study many but not all relevant attitudes with regards to labeling; most importantly, they often overlook beliefs about how people will treat individuals who are labeled mentally ill.

The researchers and theorists quoted offer important insights into the complexity of labeling in the creation of illness identity for patients with severe mental illness. Though, in some cases, they have different views on the importance of labeling as a process, they all agree that an important factor worth considering is how variations in circumstances, e.g., age and gender, make a difference in the impact of labeling on identity.

### **Gendered Differences in Illness Identity**

Gender evidently makes a significant contribution to variation in expression and internalization of illness identity. This phenomenon is an effect of the fact that gender forms a layer of identity. Seale & Charteris-Black (2008) provide insight in their paper on class, gender and illness narratives. They assert that gender performativity can be extended to the creation of illness narratives, where women are seen as more expressive of feelings, and group support or intimacy, whereas men exhibit an attachment to success and achievement as a part of their identity of "masculinity". This "hegemonic orientation" is threatened by diagnosis with illness. Evidently it offers a challenge to the acceptance of an illness narrative or identity, where "masculinity" is believed to be mutually exclusive to the vulnerable state of severe mental illness. On the other hand, their findings indicate that women do not experience illness as a threat to their "womanhood"; rather, the state of increased vulnerability often leads to an increased need and search for support groups or community. Here, we see that women will seek to form an identity post diagnosis at the level of the group.

The idea of gendered differences in perception of mental illness and its effects on illness identity are further explored by Boysen, Ebersole, Casner, & Coston (2014), who offer the concept of gendered social stigma associated with mental

illness. Here, we run into the idea of severe mental illness that is viewed as intrinsically "masculine" versus intrinsically "feminine". Men have been shown to exhibit externalization of mental illnesses, such as anti-social personality disorder and addiction, while women more often exhibit cases of internalizing disorders, such as depression, anxiety and eating disorders. However, the severity and dangerousness, as well as the public attribution of gender to mental disorders as a whole, is disproportionately unfavorable to men. This puts additional strain on the formation and acceptance of illness identity, where the actual diagnosis conflicts with the "gender-appropriate diagnosis".

For example, their study indicates that schizophrenia, though equally diagnosed among men and women, is often assumed by the general public to be a "male" disorder. This phenomenon occurs due to the attribution of "aggressive" or "violent" symptomatology that is sometimes seen in the disorder, as male attributes. How, then, would this impact the formation of an illness identity among female schizophrenics? Moreover, they suggest that biases are evident in the diagnosis labels themselves; for example, the pathologizing of traditional female sex roles as personality disorders, seen in dependent personality disorder and histrionics. People, therefore, have gendered beliefs about mental disorders, which may solidify the patient's illness identity through reinforcement or internalization.

Finally, support for the role that media plays in emphasizing gendered differences in illness, and therefore illness identity and its consequent behavior, is found in the work of Whitley, Adeponle, and Miller (2014). They performed a content analysis study of 1,168 Canadian newspaper articles, by analyzing the frequency of coded mental health themes and content and then comparing articles using Chi-square tests. Their study of newspaper reports indicates strong support for the idea of the

chivalry hypothesis; fundamentally, the proposition that media within patriarchal systems portray women with mental illness as vulnerable and worth sympathy, while men with mental illness are depicted as violent and criminal, due to their "aggressive" nature. Furthermore, articles referring to women's severe mental illness showed significantly more themes of recovery, compared to those of men, which emphasized stigmatizing themes of criminology. These portrayals may be internalized in the formation of illness identity by the patient and labels by the public.

These studies, therefore, provide evidence for gender as a mediating factor in the creation of illness identity, as speculated by participants in the creation of labeling theory discourse (Link et al., 1989; Weinstein, 1983), but they also indicate a further mediating factor in the outcomes that illness identity creates; namely, stigma and stigmatization as a result of illness identity.

### **Stigmatization and Illness Identity**

As is apparent from the previous section of this review, there is a role to be played within the formation of illness identity by stigmatization and stigmatizing beliefs. Evidence for this is found in the work of the authors discussed below.

Dinos, Stevens, Serfaty, Weich, and King (2004) conducted a qualitative study of 46 individuals from North London diagnosed with severe mental illness, to determine their experience of stigma and the role it played in their self-perceptions. They used the patients' descriptions of their diagnoses as the most relevant reports of illness. They begin their paper with an assertion of the findings of Goffman (1990) that mental illness stigma presents two threats to the identity of the diagnosed individual. It is discrediting (where the illness is overt and noticeable) and discreditable (where the illness can be concealed). However, in their opinion, the extent to which stigma plays a role in mediating self-perception would depend on



factors such as the nature of the illness, its severity and the individual's readiness to reveal their diagnosis (described as concealability by Corrigan & Watson (2006)). They postulate that stigma presents itself in two forms; either subjective stigma, which is always a direct consequence of the diagnosis label and describes the feeling of being stigmatized even in the absence of actual discrimination; or, objective stigma which is overt discrimination, including increased social distance by members of the public (in the case of psychotic disorders) and increasing patronization (in the case of non-psychotic disorders). Both these forms of stigma bear effect on the individual's self-perception and resulting behavior.

They further indicate the consequences of stigma as increased feelings of anger, depression, fear, anxiety, isolation, guilt, embarrassment and justification for avoidance behavior. Here, we read a direct impact on identity once illness and its stigmatizing notions are assumed (internalized stigma); the individual views themselves as justly discriminated against and as unable to function independently, thereby increasing a sense of inferiority post diagnosis. One example of this is found in the response of one of their participants, who indicated: " 'Schizophrenic is the worst diagnosis because I've heard it in the newspapers and on TV, that they are really mad schizophrenic people, they are very dangerous to society, they've got no control. So obviously I came under that category.' (African / Caribbean woman 41, schizophrenia)" (Dinos et al., 2004, p. 177). Particular therapy modalities, including the use of lithium prophylaxis and electroconvulsive shock therapy further increased feelings of stigma.

Dinos et al., however, indicate some positive outcomes of an assumed illness identity. They found that, in some cases, participants who had come to terms with their diagnosis and accepted it as a new part of their identity, were better adjusted as

they viewed their illness as an indication of their resilience; strength became a part of their new identity, informed by their perception of illness, which was apparently not skewed by negative stereotypes and stigmas.

Their findings are solidified when read in the context of the findings of Corrigan and Watson (2006), whose review of literature produced the following ideas. Firstly, stigma works against diagnosed individuals in two ways; it prevents them from achieving important life opportunities, which affects their previously held notions of self-concept, e.g., the employed self or the student self. Because patients live within cultures steeped in stigmatizing beliefs about mental illness, they inevitably accept these beliefs as fact, leading to decreased esteem and efficacy. A clear example of this is seen in their citation of Kathleen Gallo, who post diagnosis described herself as "a person with a serious mental illness" and therefore took on the identity of the "social garbage heap" (p. 35).

Corrigan and Watson make a significant contribution to the literature of stigma and self-perception in mental illness with their formulation of the fundamental paradox of self-stigma. Essentially, though prejudice and stigma are likely to have a definitive negative effect on self-concept, two other possible outcomes may arise. In the first instance, diagnosed individuals aware of the stigmatizing beliefs surrounding their illness and their resultant experience of discrimination, resort to a response of "righteous anger". They therefore become active in their own treatment process and have an increased sense of agency; their response is a sort of activism in seeking better-quality service and understanding their diagnosis, akin to the "educational response" (Link et al., 1989). On the other hand, individuals may exhibit a response of indifference.

They provide a solution to this paradox in the explanation of situational parameters as follows. Stigmatizing beliefs are held within the public (even among health professionals) surrounding notions of homicidality, which leads to a public response of fear and exclusion. The idea that people with mental illnesses are childish leads to a benevolent reaction, and the idea that people with mental illnesses are rebellious or free spirited leads to a reaction of authoritarianism. Self-stigma does not simply occur because the individual is aware of these stigmatizing beliefs, but rather because of how they internalize them. Self-stigma, which leads to negative self-perception, thus occurs on two levels: first, the individual agrees with the stereotype, and then they adjust their behavior and identity in line with the stereotype. In this context, therefore, "righteous anger" is a healthy mechanism that protects the self-concept from being totally engulfed in the stigmatized identity.

They continue with their analysis by indicating that response to stigma is not necessarily a set trait of the individual but rather results from the situations they are exposed to. The individual's perception that the discrimination they experience is legitimate regulates their esteem response; high or low esteem is determined by how right the individual believes the public stigmatizing response to their diagnosis to be. On the other hand, their perceived identification with the diagnosis label at the in-group level facilitates their "righteous anger" or "indifference" response. "Righteous anger" is seen as a response here, where the individual seeks their identity from the group and sees discrimination against an individual with a mental illness as a systemic issue. Moreover, they suggest that a pervasive, internalized protestant work ethic, a cultural assertion that vulnerable states such as mental illness are the results of self-indulgence or a lack of discipline, leads to decreased esteem once a diagnosis is established.

They submit mediators of the perceived legitimacy of stigma and prejudice that affect self-perception as: (i) external versus internal attributions; (ii) self-identity-protective measures of in-group comparisons (e.g., "I am more independent than most mentally ill people", versus "I am less independent than most mentally healthy people"); and (iii) selectivity of values as self-identity-protection (i.e., a reduced value for qualities that the majority places high value on and forms stigmatizing beliefs based on access to that quality, e.g. a decreased value for success and achievement).

Finally, they propose mediating factors of the internalization of stigmatizing beliefs (self-stigma):

1. Time since the acquisition of stigma: it is more difficult to insulate self-concept from the harmful effects of stigma against a new/recent diagnosis than one that the patient has had time to adjust to.
2. Concealability of stigma: here, they suggest a conflict in the literature. On the one hand, concealed illness protects from overt discrimination and thus has a decreased effect on self-concept, while, on the other, concealed illness reduces the chances of group identification; thus, the individual may perceive themselves as uniquely deviant, decreasing positive self-concept.
3. Responsibility for stigmatizing condition: individuals who see themselves as the source of their illness state (e.g., those with a highly internalized protestant work ethic) have significantly lowered esteem.

The concepts of self-stigma or the internalization within the realm of mental illness have continued to be an area of interest in more recent literature. Lucksted and Drapalski (2015) describe findings from multiple studies by 30 researchers at a conference held in October 2013 surrounding themes of stigma and self-concept within mental illness. Their findings propose that, for the most part and in a general

sense, self-concept is constructed vis a vis the perceptions others have of an individual. Therefore, negative perceptions are internalized, leading to a sense of shame. This is similar to the findings of Dinos et al (2004), in that negative views held by others are internalized as negative views of the self and lead to negative self-concept. Lucksted and Drapalski further indicate that the effects of this internalization include a decreased sense of empowerment, hope and positive recovery outcomes, as well as increased psychiatric symptomatology. Due to the pervasiveness of negative depictions of mental health, they suggest that it is almost impossible to avoid this internalization. Here, they depart from both Dinos et al. (2004) and Corrigan and Watson (2006), who allow for situations in which stigma may not be internalized.

Researchers who attended the same October conference confirmed the hypothesis that the ideas and features an individual assigned to a mental illness label, even prior to their diagnosis, had a significant impact on the way that individual viewed themselves (formed identity) with that same diagnosis. Moreover, the researchers found that prior experiences of discrimination would lead people with a diagnosis to anticipate stigmatization and hold an increased expectation that the stereotypes held against people with mental disorders held true. This phenomenon was found to be true in a separate study from the same conference, which indicated that people with a diagnosis tend to mentally rehearse how they would behave in a potentially stigmatizing situation, as they have decreased confidence in their psychosocial capabilities.

Some further noteworthy findings indicated in this article include the notion that the perception of "being a person seeking treatment" influences outlooks and attitudes of the individual toward seeking treatment. Additionally, the effects of self-stigma extend to a diagnosed individual's willingness to maintain their medication

regime, and there are added negative effects of multiple stigmatized identities (e.g., as relates to class, gender and sexuality) on the self-concept of diagnosed individuals.

The idea of multiple stigmatized identities having a tangible effect on the experience of self-stigma within self-concept post diagnosis is countered by the findings of Muñoz, Sanz, Pérez-Santos, and Quiroga (2011), whose quantitative data show that sociodemographic variables, as well as diagnosis, psychotic interval and duration do not have significant effects on the level of internalization of stigmatizing beliefs. Rather, high self-stigma is observed in individuals who experience alienation, discrimination and social isolation. Interestingly, they stress that discrimination in an individual's direct or closest environment, e.g., the family, has a higher impact on self-stigma than broader societal stigmatization.

However, similar to Lucksted and Drapalski (2015), this article indicates a relationship between experienced stigma (what Lucksted and Drapalski describe as "prior experiences of discrimination") and decreased self-worth. In this case, specifically, the instance of stigmatization leads the individual to believe they have poor personal mastery and, therefore, they develop self-contempt.

Finally, in their work on the impact media have in facilitating the formation of self-stigma by people with a mental illness diagnosis, Goepfert, Heydendorff, Dreßing, and Bailer (2019) provide the final piece necessary for our understanding of stigmatization and illness identity. They conducted an experimental laboratory trial in Germany with 180 patients aged between 18 and 70 years old and excluded participants with psychotic, manic or hypomanic episodes and suicidal ideation. They observed participants affect and stereotype agreement after exposure to media with mental illness themes in order to determine the process through which stigma is internalized. They indicate that negative events involving persons with known mental

illness are largely covered through a sensationalist lens, where the focus is on mental illness as "dangerous", "criminal" or a "burden to society": in many ways, this notion echoes the work of Whitley, Adeponle, and Miller (2014). They provide an illustration in the coverage of the 2015 Germanwings plane crash, where the pilot was diagnosed as having depression, as an instance where priming the audience about mental illness, then reporting on violent events inevitably encouraged them to form a causal link. This presents a challenge to individuals trying to form a self-conception post diagnosis while consuming the same stigmatizing media. They suggest a 4-step pathway to internalized stigma: (i) stereotype awareness; (ii) stereotype agreement; (iii) self-concurrence (internalizing); and (iv) self-harm (in the form of lowered esteem). This model is strikingly similar to the components suggested by Corrigan and Watson (2004), though it includes two new steps.

With these steps in mind, Whitley et al. (2014) conducted a study and found that participants indicated overwhelming stereotype agreement and negative affect after one viewing of a film that portrayed their mental illness diagnosis (in this case depression) in a negative light. Moreover, and again in support of the findings of Corrigan and Watson, stereotype awareness was not affected by agreement; participants could either agree or disagree with the stereotype, but were constantly aware of the stereotype at hand. They suggested that people with mental illnesses use traditional media as information sources for their current state. In fact, they found that a higher severity of illness led to higher motivation to seek information from traditional media. The content itself played a decisive role; where the material provided was largely educational or informative, participants exhibited no self-stigmatization. Moreover, in the case of films, characters portrayed as pitiable did not decrease self-stigma, while those portrayed as having positive emotions did.

The literature shows overwhelming support for the model of stigma as a mediating factor in the formation of illness identity. Moreover, the process by which this occurs is evident across the board; that is, awareness, either through the overt or subjective experience of stigma, elicits a response of agreement or disagreement with the stereotype associated with one's diagnosis, and thus affects the behavior exhibited.

It is interesting to note the distinction in studies of the mediating factors of this process; i.e., the differences in emphasis on sociodemographic factors and the role of media. Moreover, it is evident that in some cases, stigma is a non-factor in the formation of illness identity. There is, however, a direct impact of the resulting self-concept on possible recovery outcomes.

### **Recovery Outcomes as Mediated by Illness Identity**

#### **Positive Outcomes**

Illness identity viewed through the lens of increased insightfulness has several positive recovery outcomes. This is stipulated in the contribution of Klaas et al. (2016), whose multi-level analysis of treatment of early-phase psychotic symptoms in patients with severe mental illness contributes several important findings. The research team analyzed the functioning of 240 patients (69% male) in Lausanne, Switzerland, aged between 17 and 37 years old, 8 times, over three years. First, this article asserts that patients diagnosed with severe mental illness experience internal conflict between accepting their status and concealing it due to its stigmatizing nature. However, those who increase their insight into their state and opt to, instead, transform their identities to accommodate their diagnosis have increased psychosocial and occupational functioning. Insight, in their work, is stipulated as dependent on acknowledgement of illness identity. Evidently, in the early stages of their experience



with psychosis, participants opted for denial strategies, as these served to protect their ideas of self from stigma; however, over time, denial strategies offered a challenge where the illness presented real life consequences. Thus, recognizing and accepting the illness had positive effects that included improved relationships with caretakers that led to a better social treatment context, and increased self-esteem and self-protection mechanisms against stigma and negative stereotyping.

Moreover, increased insight was positively correlated with increased self-reported life satisfaction and decreased depressive symptomatology measured over time. Here, Klaas et al. note that depressive symptoms may spike at the beginning of the process as a result of internal conflict, but normalize and decrease over time once the illness is accepted as part of the new "transformed" identity. They further suggest that adherence to illness identity maintains patients' high esteem and psychosocial functioning. This study, therefore, proves that identity processes within the context of diagnosis mediate recovery outcomes in a positive light. However, the authors note that, after one year, the effects of insight are significantly less poignant.

More support for the positive outcomes of illness identity in recovery is found in the work of Mizock, Russinova, and Millner (2014). They conducted a qualitative content analysis of semi structured in depth interviews with 16 family caregivers and analyzed data through a conventional content analytic approach. The study, conducted in Iran focused on families with patients with schizophrenia, schizoaffective disorders and bipolar affective disorders. Their findings are not only in agreement with those of Klaas et al. (2016) but also assert a more expansive list of positive recovery outcomes reported as a result of acceptance of illness identity. These include increased awareness of assets, strength of relationships, empathy for others, problem solving, enhancement in life, community integration and medication adherence (p. 1266).

Their main assumption is that a positive sense of self which incorporates illness identity forms when individuals follow one of the following profiles: an acceptance of illness but rejection of the illness label; a rejection of the illness label and search for new terminology that encompasses the individual's experiences; and the use of passive/ selective insight or integrative insight strategies.

Finally, Marcos, Cantero, Escobar, and Acosta (2007) introduce the idea of locus of control, as it relates to illness identity, into the literature. Locus of control is the degree to which individuals feel they have control over their life experiences and outcomes compared to the control of external forces. Marcos et al. conducted questionnaires among 98 female eating disorder patients at the University Hospital of San Juan in Spain. The participants were aged 12 to 34 years old and had a mean length of 3.8 years of illness and 16.85 months of treatment (Marcos et al., 2007, p. 375). Essentially, Marcos et al.'s study of the relationship of patients with eating disorders to illness identity found that a strong acceptance of illness identity had a strong correlation to increased beliefs of internal locus of control; hence, the idea that the disorder was curable. This positively impacted emotional and psychosocial adjustments and adaptive behavior, as well as increased hopefulness, which is necessary for recovery. Their findings, therefore, give credence to the work of both Klaas et al. (2016) and Mizock et al. (2014) who suggest illness identity leads to better medication routines as patients have more belief in these treatments.

### **Negative Outcomes**

A conflict arises in the literature, where illness identity is seen as impacting recovery outcomes. Though the findings in the previous section support the notion of positive outcomes, there is equal and substantial support for the notion of negative outcomes. Baker, Procter, and Gibbons (2009) provide compelling evidence for the

sense of loss that comes as a result of the acceptance of illness identity and is often ignored in the therapeutic process, leading to negative outcomes. Their extensive review spans nine databases and covers work from 1994 to 2009 referencing adult and adolescent experiences of loss of a sense of self within mental illness.

Their work suggests that acceptance of diagnosis labels as a new assumed identity leads to a loss of pre-diagnosis identity, which destroys the individual's self-concept and causes feelings of shame, helplessness and hopelessness, despair, ostracism, failure, distress, victimhood and inferiority, as well as a loss of previously held identity roles (e.g., the self as a parent). These states hinder recovery. Moreover, they indicate that other dimensions of loss, including perceived loss of abilities, loss of employment, opportunities, relationships, family, friendships, and anticipated losses lead to increased suicidality. Evidently, acceptance of illness identity by a diagnosed individual evokes negative emotions within the communities surrounding that individual, who opt to ignore the resulting losses and grieving process that the individual experiences, thus perpetuating their stigmatizing experience and marginalization. Denied grieving hinders the recovery and reintegration of individuals who accept their illness identity.

Further support is found in the work of Buckley-Walker, Crowe, and Caputi (2010), who offer that acceptance of illness identity leads to a discrepancy between the "ideal self" and the "current self", i.e., it may lead to a loss of positive self-concept. This state, left unacknowledged, leads to increased psychological distress, and a decreased sense of agency, which causes disempowerment at the level of treatment decisions and increases hopelessness.

Cruwys and Gunaseelan (2016) provide evidence for stigma-informed illness identity as harmful to the recovery process. They conducted a survey of 250

participants (64% female) diagnosed with at least moderate clinically severe depression. The mean age of participants was 27.37 years old and they originated from numerous countries across the globe including the United States, Australia, India and 20 other countries. They postulate that patients with strong illness identity are not likely to exit their mental illness support group, i.e., their identity is in many ways sustained and informed at the group level.

Here, they suggest, lies the key concern for recovery outcomes. Groups defined by similarity of diagnosis or label hold certain norms, which provide the "content" of illness identities. These norms support thoughts (e.g., hopelessness) and behavior (e.g., self-harm) that are in line with the diagnosis and worsen existing symptoms. A high level of group identification was found in their study to directly increase group conformity and, therefore, reduce wellbeing. Essentially, they propose that the very notion of illness suggests a lack of wellbeing; it follows that identification with illness is to accept oneself as unable to experience good health or wellbeing.

Their findings, therefore, not only prove a correlation between illness identity and poor recovery outcomes, but also provide parameters not previously identified for this to be the case, i.e., group identification (accepting the illness label and assuming membership within a group of patients with the same label) and not categorization (the actual diagnosis) has a negative impact on recovery. They therefore suggest mitigation of the consequent negative outcomes by challenging the legitimacy of stereotypical notions and encouraging patients to view their illness as a temporary state, i.e., the illness state and not the actual diagnosis, rather than permanently biochemical.

Finally, Markowitz, Angell, and Greenberg (2011) introduce the idea of reflected appraisals, especially from close family members, as mediating negative recovery outcomes, once a patient has assumed an illness identity. They suggest that people who accept illness identities feel demoralized and form self-fulfilling prophecies, which lead to a reduced self-reported quality of life, thus impeding recovery. Further, the extent to which people view themselves in terms of their stigmatized illness plays a role in mediating symptoms and functioning. They claim that families who experience "courtesy" stigma as a result of their approximation to the individual who has assumed an illness identity (in the sense that the individual has lost all other identity roles and is viewed primarily through the lens of their illness) act in further stigmatizing ways towards the ill individual, further increasing their depressive symptomatology. Their study finds that adult individuals with severe symptoms and high illness identity are perceived by their mothers (or close family members) as less competent, capable, healthy and as having a lower sense of control. The individuals become aware of these perceptions, either overtly or through subtle cues, and reflect these appraisals as self-appraisal; this is then correlated to increased risk of symptom relapse. They specify that, even if the individual is in a highly stable environment, symptoms, self-efficacy and life satisfaction, all measures of recovery outcomes, are negatively affected by stigmatized self-appraisals which are informed by reflected appraisals, so that internalized familial shame that comes from identifying with illness leads to behavior that impedes recovery.

### **Discussion**

The literature provides evidence for a relationship between illness identity and recovery outcomes among adults with severe mental illness, with several mediating factors from the diagnosis stage. Chief among these is the repeated allusion to a sense

of loss of dimensions of identity (Baker, Procter & Gibbons, 2009; Baldwin, 2015), that leads to a spectrum of reactions, including withdrawal, concealment, (negative reactions) or a sense of increased agency and a need to become active in the recovery process.

Though the individual's agency, as relates to the creation of their illness identity, plays a major role in determining outcomes, there has also been an emphasis on the role society plays in the reinforcement and creation of the content of illness identity. This role is either through the creation of stereotypes in traditional media or through active subtle or overt discrimination and stigmatization, which fosters a sense of "otherness" within the diagnosed individual. However it is important to note that the current literature does not offer unanimous support for stigma as a major factor; it is also probably dependent on variability in sociodemographic factors.

There is a repeated and evident need to look into the ways the clinical environment itself facilitates the proliferation of stigmatizing beliefs, which are then internalized by patients. One aspect of this is presented in the distinction between evidence-based-medicine, as would be seen in the strictly psychiatric approach to illness, versus the more narrative-based approach, where patients understand their illness through the lens of story, as is seen in the psychological approach, especially positive and humanistic psychology.

It is apparent that the emphasis of the first approach on illness as a sort of permanent biochemical state hinders a self-concept, whereas the notion of illness as a temporary state, just a part of the individual's story and not their identity, has more useful and positive outcomes. There is, however, a need to maintain awareness of diagnosis to ensure that the patient does not succumb to the consequences of a lack of management of their symptoms. Primarily, the patient should be encouraged to

understand and participate in the treatment process and gain new identity in the sense of self as an empowered advocate of mental illness, rather than remain passive and labeled, as it would be difficult to transform their identity beyond the label.

Labeling theory is seen as the strongest foundation on which to base models of illness identity and its impacts on recovery. This is because it is not only the most prevalent theory, repeatedly referenced across the articles reviewed, but also because it has been subject to criticisms and counter-criticisms spanning at least 5 decades (from Goffman's original conception in 1963), and has therefore been modified to better accommodate concerns of the earlier false notion that illness labels themselves cause negative outcomes; rather, it is a patient's reaction to the label that causes varied outcomes.

Current literature provides a dilemma, where there has been no clear marrying of the sociological and psychological approaches to illness identity; there is, therefore, a need to conduct more interdisciplinary research into the mechanisms of illness identity. Additionally, it appears that the consequences of an illness identity are not the result of the diagnosis itself, but rather the perceptions that surround the diagnosis. Illness identity, then, forms on either a positive or negative scale, and this is what impacts recovery outcomes. A rough model of this process is seen in Figure 1 in the appendix section.

Implications for clinical practice are also evident from the literature reviewed in this paper. The first is a need for clinicians to challenge perceptions when providing a patient with a diagnosis. This should include an emphasis on the notion that, while the diagnosis itself may offer lifelong consequences, it is not in itself an all-encompassing facet of identity. Affliction is, therefore, a temporary state and the individual can live a healthy and normal life despite their diagnosis.

There should be a focus on family therapy, as it is within this sphere that societal perceptions are endorsed or reinforced. An individual whose family system views them solely through their diagnosis label, either through subtle reflected appraisal or overt reactions of authoritarianism, patronization or rejection, risks denying the individual the opportunity to form a transformed and positive identity post diagnosis, which would hinder recovery. This situation would deny them the ability to reinhabit their previously held roles (e.g. self as parent), leading to demoralization and poorer outcomes. Moreover, there is a need to recognize and endorse the grieving process within therapy; grieving the "lost self" and missed opportunities to allow the diagnosed individual to move on, i.e., to allow identity transformation.

The therapeutic process should focus on engaging the diagnosed individual to determine motives for recovery. This would not only increase a sense of hopefulness, but also encourage the individual to visualize their "ideal" future self through the lens of possible opportunities for independence, thus protecting their self-concept.

The literature reviewed evidenced certain limitations, including too much focus on chronic illness (which is a broad spectrum), rather than a specific focus on different diagnoses. Additionally, the data presented was almost always qualitative, which hinders the extent to which findings should be generalized. There were, however, promising gaps for future research, including the need to further define parameters which influence the adoption of a positive, rather than negative, illness identity, the need to further investigate the role of support groups in the formation of illness identity and its impacts on recovery and the impact of relapse and multiple diagnoses as mediating factors.



### **Conclusion**

In conclusion, illness identity is an important factor in the recovery process of adults with severe mental illness. Its development from the diagnosis stage reveals important mediating factors, including perceptions of stigma, gender, and the views of others, especially at the family level. It has a noted impact on self-perception, which in turn determines the trajectory of recovery. Therefore, the literature reviewed in this paper offers several implications for the clinical setting, as well as indicating the need for further research on the mechanisms of the relationship between illness identity and recovery.

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## Appendix

### Flowchart Showing The Relationship Between Illness Identity and Recovery

#### Outcomes

**Figure 1:**

*Rough Model of The Process of Recovery Vis-a-vis Illness Identity*

