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Recovery and Serious Mental Illness: A review of current clinical and research paradigms and future directions

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Abstract

Introduction: Recovery from serious mental illness has historically not been considered a likely or even possible outcome. However, a range of evidence suggests the courses of SMI are heterogeneous with recovery being the most likely outcome. One barrier to studying recovery in SMI is that recovery has been operationalized in divergent and seemingly incompatible ways, as an objective outcome, versus a subjective process.

Areas Covered: This paper offers a review of recovery as a subjective process and recovery as an objective outcome; contrasts methodologies utilized by each approach to assess recovery; reports rates and correlates of recovery; and explores the relationship between objective and subjective forms of recovery.

Expert Commentary: There are two commonalities of approaching recovery as a subjective process and an objective outcome: (i) the need to make meaning out of one's experiences to engage in either type of recovery and (ii) there exist many threats to engaging in meaning making that may impact the likelihood of moving toward recovery. We offer four clinical implications that stem from these two commonalities within a divided approach to the concept of recovery from SMI.

Key words: serious mental illness, recovery, remission, recovery-oriented practice, outcomes

Due to many factors, including persistent pessimism among mental health professionals and divergent views on the nature and course of serious mental illness (SMI), recovery from serious mental illness was historically not considered a likely or even possible outcome. SMI is an umbrella term that includes multiple diagnostic categories that share similar levels of disability [1,2], however this pessimism is particularly prominent in views of schizophrenia and thus much of the research has focused on schizophrenia. For example, once influential Kraepelinian models of schizophrenia considered schizophrenia to be a deteriorating illness. In this view “stability” was cast as the most positive outcome from schizophrenia such that those who did recover were assumed to be incorrectly diagnosed.

A series of quantitative and qualitative studies, however, provide considerable evidence that SMI does not follow one course characterized by lifelong dysfunction. Instead, tracking individuals with SMI for extended periods has repeatedly shown a variety of outcomes. These studies indicate that even amongst the most severely ill, individuals were more likely than not to recover in many meaningful ways, frequently achieving symptom remission and a return to functioning [3-8]. In parallel, first person reports and qualitative studies of the subjective experience of SMI recovery [e.g. 9-13] portray a complementary set of recovery outcomes. These works consistently report that despite bewildering symptoms, experiences of stigma, demoralization, and trauma, persons with SMI are able to recover a sense of dignity, hope, self-direction, coherent sense of identity, and the achievement of an acceptable quality of life. These findings emphasize the necessity of examining dimensions of wellbeing beyond symptom remission.

Taken together, the earlier amongst these studies helped spark a grassroots movement in the 1980s and 1990s that ushered in a new conceptualization of what the outcomes for those with

SMI should entail [14]. The recovery movement signified a paradigm shift in the conceptualization and treatment of SMI, and as with any paradigm shift, raised many questions for scientists, practitioners, and consumers alike. Response to these questions included a widely-cited definition offered by Anthony [15] describing recovery as “a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness” [p. 527]. In 2005, there was a seminal meeting by SAMHSA [16] involving panelists from divergent backgrounds who developed a list of 10 essential elements of recovery: Self-direction, Individualized, Empowerment, Holistic, Non-linear, Strengths-based, Peer Support, Respect, Responsibility and Hope.

The recovery paradigm has also raised important questions concerning how often recovery occurs and what helps and hinders recovery outcomes. To address these questions, Silverstein and Bellack [17] summarized two decades of research on recovery. They noted, however, that beyond establishing that recovery is a meaningful and realistic outcome, that this literature was beset by confusion regarding how recovery should be defined and measured. In response, they identified four areas of research and development: 1) the definition of recovery; 2) the development of reliable measures of recovery; 3) rates of and barriers to recovery; and 4) the effectiveness of recovery-oriented care.

Since this important review, the volume of work on recovery from SMI has significantly increased. In this review, we explore the ways in which the literature following Silverstein and Bellack’s [17] review has defined and measured recovery. The current paper is an attempt to explore the newly emerging literature as well as to consider divergent views of recovery, and will be divided into six sections. First, we will focus on the emergence to two distinct ways of

defining recovery: recovery as a subjective process and recovery as an objective outcome. Second, we will contrast the methodologies both approaches employ to measure recovery. Third, we will present findings regarding the rates and correlates of recovery. Fourth, we will explore the relationship of objective and subjective forms of recovery. Fifth, in our commentary, we will discuss two commonalities of approaching recovery as a subjective process and an objective outcome in an attempt to bridge the divergent views and will discuss four implications for recovery oriented care. Finally, a view of key needs for future research will be offered.

Our review was based on literature searches utilizing PubMed, SCOPUS, PsycInfo, and EBSCO databases with search terms schizophrenia, recovery, outcome, treatment, serious mental illness, remission, and process. We included articles that had been published since Silverstein and Bellack's [17] article as well as foundational articles contributing to the history and course of the recovery movement in SMI. In an effort to capture a larger sense of the recovery literature, we chose not to limit the review to articles focused solely on schizophrenia, instead including a number of relevant articles pertaining to SMI as a more general category. Abstracts were examined to determine if the article presented findings regarding recovery or remission rates, recovery outcomes, recovery-oriented care, or definitions of recovery. Articles including information on these topics are in the following review.

1. Review

1.1 Contrasting Views of Recovery as a Subjective Process and as an Objective Outcome

In their 2008 review of literature on recovery from SMI, Silverstein and Bellack [17] noted a primary barrier to the study of recovery was differing definitions of the concept of recovery. They suggested one set of work conceptualized recovery as an outcome occurring after a successful treatment or series of gains made by the person diagnosed with SMI while a second

set discussed recovery as something that emerged as a person made their way through life. This view was in part an evolution of Davidson and Roe [18] who identified two distinct uses of the word recovery: recovery *from* illness (i.e., outcome), and being *in* recovery (i.e., process). Davidson and Roe [18] further distinguished these approaches by the type of person who was responsible for determining whether recovery had occurred. Recovery as an outcome was naturally dependent upon a determination made by someone other than the individual (e.g. a clinician rating of symptom severity) while recovery as a process places primary emphasis on the subjective experiences of the person. Although this division of recovery definitions reflects a prominent demarcation in the literature, other models have been proposed, including a conceptualization of recovery as consisting of three elements: cure, illness management, and personal recovery [19]. For the sake of this review we will focus on the more prevalent divide with views falling into either subjective process or objective outcome, but acknowledge that there are some who have proposed models that fall somewhat outside this dichotomy.

Since 2008, the general divide between process and outcome has continued; for example Kane [20] framed recovery as an outcome and proposed that it is the product of a number of steps beginning with successful engagement in pharmacological treatment, which leads to the remission of symptoms, and finally recovery as defined by achieving specific outcomes observable by others within a time frame (e.g. successful levels of psychosocial function for two years). Notable in this view is that clinicians have primary responsibility in terms of making accurate appraisals regarding whether the client achieves recovery, and that recovery is defined by a level of functioning and the remission of symptoms rather than on the subjective experiences of the individual experiencing SMI. These approaches tend to rely on traditionally paternalistic views of SMI and often neglect the considerable disagreement between providers

and clients with regard to clients' quality of life, as clients tend to report better outcomes than their providers [21,22].

In contrast to this, is a different approach often carried out by phenomenologists, advocates, and persons diagnosed with mental illness themselves [23,24]. Summarizing this work, Slade and Longden [25] frame recovery as something subjective and unique across different persons. They refer to this as "personal recovery" and frame it as a process defined and assessed by the person themselves. They argue that this is in contrast to the view focused on remission, and instead emphasize commonalities across human experience, such as experiencing struggles and searching for fulfillment. They question the need for acceptance of a diagnosis to achieve recovery. Support for this model can be found in direct interviews with persons with SMI. Further evidence comes from Law and Morrison [26] which compiled understandings of recovery from 381 persons who had personal experience of SMI and which emphasized a personally acceptable quality of life.

Synthesizing this work, Drake and Whitely [27] call attention to the dangers of this divide, arguing that "the rapid proliferation of definitions, models, and research on recovery makes it vitally important to examine the data to disentangle the evidence from the rhetoric" [p. 237]. Like Slade and Longden [25], they emphasize that the view of recovery as an outcome neglects data from autobiographical studies that the experience of recovery involves gaining a sense of agency and autonomy in the face of difficulties. They further note that any treatment which progresses without concern for the experiences of individuals utilizing treatment risks its outcomes being meaningless. Offering empirical evidence of the divided views of recovery, Karow et al. [28] interviewed 131 persons diagnosed with schizophrenia, their family members, and psychiatrists regarding perceptions of remission. They found agreement in less than 20%

across the three groups, with different experiences being offered different weights by each group. For example, persons diagnosed with SMI valued subjective well-being substantially more than other outcomes such as symptom reduction. Similarly, Kuhnigk et al. [29] interviewed 105 adults diagnosed with mental illness, 160 physicians, 50 relatives of persons diagnosed with mental illness, and 30 payers responsible for the costs of care, regarding their appraisal of the most important outcomes. Not surprisingly, groups differed in their ratings with pairwise agreement ranging from 38.9% to 63.3% and rank correlations ranging from 0.43 to 0.51. The authors echo Drake and Whitley's [27] comments, though in a more optimistic manner, and recommend that stakeholders better understand each other's preferences.

Divergent definitions of recovery have thus led to a range of measurement methods and conceptualizations of outcome. We will review each, with consideration for how recovery was defined. Of note, we find problems with the terms objective recovery vs subjective recovery and use of these terms warrants consideration. The field uses the term "objective" to refer to judgments made by clinicians, often in contrast to judgments made by the individual experiencing mental illness, referred to as "subjective." Our use of these terms is not intended to suggest that judgments made by professional staff are more valid or reliable than those of the individual involved. Rather, these are two different angles of looking at an individual's experience and functioning and one should not be privileged above the other.

1.2 Methodological Approaches for Defining Recovery as an Objective Outcome

Despite symptom remission being a primary focus of recovery as an objective outcome, there are considerable differences among operational definitions. The most commonly used assessments of symptoms in schizophrenia are the Positive and Negative Syndrome Scale [PANSS; 30], the Scale for Assessment of Positive Symptoms [SAPS; 31], the Scale for the

Assessment of Negative Symptoms [SANS; 32], and the Brief Psychiatric Rating Scale [BPRS; 33]. To operationalize symptom remission, the Remission in Schizophrenia Working group has developed criterion for remission for each of these scales [34]. For the PANSS, symptom remission was defined as six months of having ratings of no more than mild levels on the PANSS symptom scales. Remission on the BPRS was defined similarly as mild or lesser levels of symptoms for at least a period of six months. For SANS and SAPS, remission was defined as mild or less levels of symptoms.

To capture objective markers of recovery in terms of psychosocial functioning, the most widely used instrument was the Global Assessment of Functioning [GAF; 35]. The GAF is a 100 point scale that offers scores of functioning based on psychological, social, and occupational functioning. Across studies, recovery as assessed with the GAF has been generally defined by a rating of “81” or higher. This rating reflects “absent or minimal symptoms” and is thought to describe overall good functioning with little to no impairment from mental health symptoms.

Other common measures to assess psychosocial functioning include the Social Occupational Functioning Assessment Scale [SOFAS; 36], the Personal and Social Performance Scale [PSP; 37], the Social Adjustment Scale-II [SAS-II; 38], and the SF-36 [39]. Similar to the GAF, the SOFAS offers a score based only on social and occupational functioning, independent of overall symptoms. The range of scores falls from 0-100, with higher scores reflecting better functioning. The PSP is an adaptation of the SOFAS and offers a score ranging from 1-100 based on ratings of functioning in four areas: socially useful activities, relationships, self-care, and disturbing behaviors. Scores falling within 71-100 indicate mild or no difficulty and is often considered indicative of objective recovery. The SAS-II offers two scores of social functioning: social and leisure functioning, which reflect level of social activities and meaningfulness of

interpersonal relationships; and instrumental role performance, which offers information about the consistency and effectiveness of role performance.

In an effort to integrate these measures, Liberman et al. [40] have proposed recovery be reflected by ratings of moderate or less on the BPRS symptom scales *coupled with* part time work or satisfactory role function, independent living and active social connections over a two-year period. This approach thus allows that recovery can occur despite higher symptoms levels than those specified in the Andreasen [35] criteria.

1.3 Methodologies for Defining Recovery as Subjective Process

Quantifying recovery as a subjective process is complicated, as it involves capturing a deeply personal process in a way that allows for comparisons between persons. Despite this challenge, several qualitative studies have explored how persons with SMI identify recovery with a fair degree of consistent results. In a study of 58 individuals with SMI, Schön and colleagues [41] found that social connection was the overall most important aspect of recovery identified by persons diagnosed with SMI. This is consistent with Topor et al. [42], who concluded based on qualitative analyses that recovery is experienced primarily in a social context. It is also consistent with findings that negative social experiences are a barrier to recovery later in life as they complicate these forms of social connection. Evidence of this includes studies by Stumbo et al. [43] who found that a history of adverse social events, including abuse and neglect in childhood, were predictors of lower levels of recovery from SMI in adulthood and Gumley et al. [44] who found attachment style was related to subjective recovery. Cotton and Loewenthal [45] interviewed 8 persons diagnosed with SMI and reported that subjective recovery involved understanding the meaning of psychotic experiences, the

creation of alternatives to the medical model (i.e., instilling hope rather than viewing SMI chronically), and sustaining social supports.

Leamy and colleagues [46] compiled results from several such studies and noted recurrent themes across countries that individuals with SMI describe recovery as consisting of connectedness to others, hope for the future, a sense of identity, feeling empowered to make one's own decisions, and the sense of a meaningful life. Jose et al. [47] similarly reviewed 25 studies that interviewed consumers across Europe, the US, and Australia and noted themes of recovery as a non-linear process, an understanding of oneself, social connectedness, and an improvement in functioning that occurred without continuing treatment. Connell et al. [48] interviewed 20 persons with first episode psychosis (FEP) and reported recovery involved two processes closely related to meaning making, with greater subjective recovery related to the development of personally meaningful interpretation of the experience of SMI, strengthened relationships with others, and more cohesive sense of self. De Wet et al. [49] analyzed interviews of seven participants experiencing FEP and reported recovery involved rejecting stigma and recapturing a previously held sense of agency and sense of self. More recently, Yarborough et al. [50] performed qualitative analyses of 177 participants with a range of different forms of SMI. They concluded that recovery involved managing loss and gaining control over one's life. They describe "getting by" or meeting basic needs and responding to stressors and "getting back" which reflected a life in which mental illness played no significant role. Taken together, the results from these qualitative studies suggest that making meaning of one's experiences and sense of self and gaining agency is important in moving toward recovery.

Informed by clients' experiences, efforts have been made to create self-report questionnaires that assess dimensions of recovery identified as important to persons with SMI.

For purposes of this review, we will discuss the most widely cited and validated instruments. The most popular of these is the Recovery Assessment Scale [RAS; 51,52]. The RAS is a self-report measure that assesses self-perception of recovery developed from narratives of individuals with mental illness, with the final items being reviewed by individuals with SMI [52]. The scale consists of 41 items, providing a total score as well as five subscales thought to reflect elements of subjective recovery: personal confidence and hope, willingness to ask for help, goal and success orientation, reliance on others, and no domination by symptoms [53]. Acceptable reliability and validity have been reported [53-55] along with correlations with other established measures such as the Hope Herth Index, Empowerment Scale, Subjective Quality of Life, Meaning of Life, and Hopkins Symptom Checklist [53,56,57]. A 20-item form of the RAS has been developed [58] and it has been translated and studied in many languages, including Japanese [56], Chinese [59], and Portuguese [60].

While reviews of subjective recovery assessments lament the lack of a gold standard, many authors have concluded that the RAS may be the best current option due to it possessing validity via constructs developed with clients and adequate psychometric properties [56,57,61]. Criticisms of the RAS include that it may not be able to differentiate among individuals in different stages of recovery, may not capture all dimensions of recovery, such as social functioning [62] and that it neglects some aspects of recovery prominent in first person accounts, including reciprocity [63,64].

Other measures identified as possessing potential to assess subjective recovery include: Illness Management and Recovery Scale [IMR; 65], Mental Health Recovery Measure [MHRM; 66], Psychosis Recovery Inventory [PRI; 67], Questionnaire about the Process of Recovery [QPR; 68], Recovery Process Inventory [RPI; 69], and Stages of Recovery Instrument [STORI;

70]. Questions have been raised about these scales' suitability for research due to psychometric limitations or complicated administration procedures [56,57]. Detailed analyses of these and other less prominent instruments have been presented elsewhere [56,57,61].

1.4 Rate of Recovery as an Objective Outcome and Predictive factors

One benefit of focusing on recovery as an objective outcome is that recovery rates can be captured and illness course more carefully tracked. This type of data is not available for subjective recovery, as no end state can be delineated. There are several tools designed to measure objective recovery and we have presented the most used and validated instruments. Summarized in Table 1 are the general findings from 34 studies published between 2008 and 2016 for people in both early and later phases of illness which tracked whether or not they achieved objective recovery. Fourteen studies present rates of symptom remission, three present rates of the achievement of psychosocial function, and seventeen offer rates of both in the same sample.

Starting with the 10 studies examining FEP, Table 1 shows that these had follow-up periods from 6 months to 10 years. Rates of symptom remission ranged from 37-91.4% while rates of healthy psychosocial functioning ranged from 29-58%, and rates for achieving both symptom remission and psychosocial functioning ranged from 14-29.5%. Considered as a whole, the average rates of recovery from FEP were 64.5% for symptom remission, 39.7% for healthy psychosocial functioning, and 21.0% for those achieving both symptom remission and psychosocial functioning.

The remaining 24 studies examined persons in prolonged phases of illness. The tracking periods for these studies ranged from cross sections with a single assessment up to 20 years follow-up. The first of the two studies with 20-year follow-up periods was Goghari and

colleagues [71] who examined 150 individuals. They reported that 40-45% continued to experience hallucinations, and that those experiencing hallucinations early in the course of illness were less likely to achieve symptom remission. Harrow and colleagues [72] examined 139 individuals also over a period of 20 years and reported that only 12 participants were symptom free at *every* assessment during that period, but 40% achieved both symptom remission and concurrent healthy psychosocial functioning during *at least one* of their assessments over 20 years. The remaining 22 reviewed studies reported rates of 37-89% for symptom remission, 21-53% for adequate psychosocial functioning, and 13-27 % for both symptom remission and psychosocial functioning criteria. Considered as a whole, the cross-study average rates for persons with more prolonged illness were 50.57% for symptom remission, 25.0% for psychosocial functioning, and 18.57% for both symptom remission and psychosocial functioning.

Concerning correlates of achieving recovery as an outcome, several studies note the importance of negative symptoms, which were repeatedly associated with being less likely to achieve objective recovery [73-75]. Shorter duration of untreated psychosis was also associated with achieving recovery as an outcome for individuals with FEP [75,76]. Conflicting findings exist for the role of cognitive functioning, as Hofer et al. [77] found that in 140 individuals diagnosed with schizophrenia, superior frontal lobe functioning was associated with experiencing symptom remission, while Brissos et al. [78] found no correlation between cognitive functioning and symptom remission in 76 individuals diagnosed with schizophrenia. Verma et al. [75] examined 1175 individuals with FEP and found female gender, younger age, marriage, and tertiary education to all be predictors of objective recovery.

Of note, studies found conflicting information about the role of antipsychotic medication being associated with rates of symptom remission. In their study of 268 people diagnosed with schizophrenia, Barak and Aizenberg [79] reported rates of symptom remission were significantly higher for those treated with an injectable medication over 6 months than for those taking oral antipsychotics. Tiihonen and colleagues [80] similarly found that individuals treated with injectable medications experienced less relapse in psychotic symptoms than those treated with oral medications, but also note that in their study of a nationwide database of 29,823 patients treated with antipsychotic medications in Sweden, 71.7% still experienced treatment failure (defined as hospitalization, suicide attempt, discontinuation of that medication, or switching to a different medication). In contrast, Harrow and colleagues [72] found that, in a period of 20 years, of 139 individuals over 70% of those who were treated with antipsychotic medication continued to experience psychotic symptoms, while those not treated with antipsychotic medications experienced significantly less enduring psychotic phenomena. Conus et al. [81] examined outcomes of over 100 clients consistently declining medication over a treatment trial and found 41% of that group experienced symptom remission while a third reached their definition of functional recovery, which included symptom remission as defined by a score “3” or lower on the CGI, and functional recovery, as defined by having regular activity and living independently. A study by Wunderink et al. [82] may offer an explanation of the mixed findings regarding the link between recovery and anti-psychotic medication. They conducted follow-up studies with 103 individuals with FEP, randomizing half to receive either a discontinued or reduced dose of antipsychotics after six months of symptom remission, or to receive maintenance doses of antipsychotic medication. They found that individuals receiving the discontinued/reduced dose of antipsychotics experienced twice (40.4% vs 17.6%) the rate of recovery (defined as both

symptom remission and psychosocial functioning) than individuals who received the maintenance dose. Wunderink and colleagues [82] interpreted these findings as suggesting that while antipsychotic medication may be linked with higher rates of acute symptom remission, it may also be linked with poorer long term outcomes.

Importantly, current research on recovery as an objective outcome exhibits multiple limitations. The ranges of objective recovery rates are large and the literature provides scant detail about the characteristics of people who are experiencing remission. It remains unclear how to integrate the findings from studies that assess outcome at 6 months with others that assess outcome at 20 years. Importantly, it is unclear which studies represent the spectrum of individuals who experience SMI, as individuals who never receive formal treatment or who quickly recover and drop out of treatment are rarely enrolled in research.

1.5 The Relationship of Objective and Subjective Forms of Recovery

While the majority of studies reviewed employed either an objective or subjective definition of recovery, some have explored whether achieving recovery as an *outcome* is related in any way to recovery as a *process*. Many of these have explored whether the subjective experience of recovery is related to symptoms. Roe et al. [83] investigated whether subjective reports of recovery using the RAS along with subjective reports of quality of life (QoL) were correlated with objective assessments of symptom severity using the BPRS and GAF in 159 individuals with SMI. They found that mood disturbances were related to lower QoL and lower hope on the RAS. Additional analyses indicated that the relationship between total symptom score and total score of subjective recovery was moderated by age of onset, while the impact of social support and loneliness upon self-reported recovery was mediated by QoL. Jorgensen et al. [84] examined the relationship of four assessments of symptoms with four assessments of self-

reported aspects of recovery over the course of one year among 101 individuals with schizophrenia. In contrast to the findings of Roe et al. [83], analyses revealed the total symptom score of the PANSS was linked with lower levels of overall subjective recovery on the RAS at all four measurement points, though the strength of that relationship varied, being strongest at baseline three and twelve months but quite weak at six months. Symptoms of anxiety, depression, and guilt were most closely linked with lower levels of self-reported recovery. Emotional discomfort and negative symptom PANSS components made independent contributions to the prediction of the RAS total.

Morrison et al. [85] examined concurrent assessments of psychological functioning, insight, symptoms, neurocognition, and subjective recovery from psychosis in 122 adults. They found emotional distress and a lack of sense of control had direct effects on the self-experience of recovery, while positive symptoms directly impacted recovery, mediated by emotional distress. Recovery was not significantly linked with neurocognition, insight, or negative symptoms. Law et al. [86] examined longitudinal predictors of subjective recovery among 100 participants with psychosis and included measures of symptoms, self-esteem, and hope. They found that current levels of subjective recovery were related to lower levels of emotional distress, higher self-esteem and hope, and to a lesser extent, more objective measures of functioning and symptom severity. Eisenstadt et al. [87] interviewed 16 participants with FEP and found that subjective recovery was linked to the decrease of psychotic symptoms concurrent with growth in a sense of personal agency, control over one's life, and social connectedness.

MacBeth et al. [88] similarly reported that quality of life was related to levels of symptoms and premorbid adjustment among a sample in Scotland with FEP. Beck et al. [89] gathered self-report assessments of symptoms and self-experience of recovery among 122

participants with SMI in the United Kingdom. The authors note different thresholds for the experience of recovery, but found wellness was linked with the experience of lower levels of anxiety and depression. Of note, cultural differences between these studies may be important as Hofer et al. [90] has reported that the links of symptoms to measures of stigma, self-esteem, and hope was stronger in a sample of persons with schizophrenia from Austria as opposed to a sample from Japan.

Focusing on the relationship of subjective recovery to objective levels of function, Oliveira-Maia and colleagues [91] have examined the relationship between the MHRM, a self-report measure of recovery, with the GAF, QoL, and self and clinician rated assessments of social needs in 101 individuals with SMI. They found that scores on the MHRM were correlated with each of these other scores. Norman et al. [92] examined the relationship between objectively related symptoms and measures of subjective recovery including the RAS and the Modified Engulfment Scale and measures of social support among 84 persons with FEP. Subjective recovery was found to be more closely associated with the perception one will be valued by others than with symptoms. A review conducted by Charzynska et al. [93] of 18 studies found that employment was associated with markers of subjective recovery. Hendryx et al. [94] examined functional correlates of the RAS in 153 participants diagnosed with SMI and found better subjective recovery was related to more social connection. A recent study (n=2842) reported that subjective QoL was a significant predictor of the "objective" event of future hospitalization, with lower QoL being associated with higher risk of hospitalization, within 6 months and self-report of the impact of symptoms on functioning significantly predicted 12-month hospitalization controlling for known risk factors [95]. Taking a different approach, Wciorka et al. [96] assessed the stage of recovery among 110 persons with SMI using the STORI

[70]. Participants assessed at higher stages of the recovery process tended to have both fewer symptoms and a richer sense of self less linked with mental illness. This is consistent with Windell et al. [97] who interviewed 30 individuals with FEP and reported recovery involved symptom remission, the chance to make personal meaning of illness, and a sense of control over one's life.

Examining other objectively assessable factors potentially related to subjective recovery, Werner [98] performed path analyses of assessments of wellbeing, needs, and hope among 172 individuals with SMI, revealing hope as the most powerful predictor of subjective recovery. In a study of 46 adults with SMI, Kukla and colleagues [99] found higher metacognitive capacity, or the ability to have complex thoughts about self and others, was related to less domination by symptoms and enhanced abilities to seek help from others, as measured by the RAS. This effect remained when controlling for symptoms. Thomas et al. [100] studied 250 individuals diagnosed with SMI and reported that social support domains, such as size of social network, were related to both subjective and objective markers of recovery. Notably, their results showed self-efficacy was the mediator between social support domains and subjective and objective recovery.

Other data suggest that subjective recovery is not a consequence of objective recovery, but is instead a protective factor. Kukla et al. [101] examined the link between subjective recovery using the RAS with objective rating of symptoms using the PANSS and objective ratings of the social components of quality of life using the Heinrichs's et al. [102] Quality of Life Scale. Participants were 68 veterans with SMI. No significant correlations were found between self-reported recovery and symptom assessments. They found, however, that levels of subjective recovery moderated the relationship between the two objective measures: the relationship of positive symptoms and social functioning. Specifically, participants with greater

RAS total scores and more positive symptoms had greater capacity for social relatedness and instrumental function compared to participants who had high levels of positive symptoms but lower levels of self-reported recovery. These moderating effects remained significant after controlling for ratings of negative symptoms. This finding was similar to Cavelti et al. [103] who assessed mood and subjective wellness among 142 adults with schizophrenia. They suggested the experience of recovery had a protective effect such that greater awareness of illness did not result in depression.

Lysaker et al. [104] proposed an integrative approach to defining and measuring recovery, suggesting recovery could be understood in terms of externally observable objective outcomes and two distinct subjective outcomes: i) the subjective appraisal of one's life circumstances and opportunities and ii) the subjective experience of oneself as an individual human being. They argue that this conceptualization allows for understanding recovery as a complex process in which life events and the meanings persons bestow to them influence the experience of illness and wellness. This is consistent with recent work pointing out how agency may interact with sense of self, resulting in a complex path from experience to agency to the experience of a multifaceted, cohesive sense of self culminating in self-directed recovery [105]. Importantly, as described by Hasson-Ohayon and colleagues [106], the complex nature of recovery best lends itself to be studied via mixed-methods design so as to capture a range of data that offers information about a multifaceted phenomenon.

1.6 Summary and Conclusions

While the idea of recovery is far from integrated within mainstream psychiatry, as is illustrated by its absence in the DSM 5 [107], abundant evidence exists showing recovery is possible and in fact a likely outcome for those with SMI. Nevertheless, significant divisions

remain regarding how recovery should be characterized. Considered as an outcome, recovery involves symptom remission and the attainment of psychosocial milestones. Considered as process, recovery has been described as including many aspects of self-experience related variables, such as sense of identity. Measured as an outcome, rates of recovery are promising, but vary dramatically across studies and research about the outcomes for persons who refuse or do not seek services is sorely lacking. Measured as a process, recovery is obtainable over time, although what this consists of will be unique to each individual. While the relationship between indicators of both forms of recovery is inconsistent across studies, the two seem to be related and it does seem clear that objective indicators of emotional distress are related to subjective appraisals of recovery.

2. Expert Commentary

Two questions emerging from this review are why this division persists and whether views of recovery as an outcome and recovery as a process have anything in common? In response to the question about why these views persist, we suggest the root of the difference may be attributed, in part, to providers of mental health services and persons with SMI being concerned with different aspects of SMI. Providers appear focused on what they and others perceive as odd and unusual experiences, paucity of internal experience, and psychosocial impairments. Alternatively, persons diagnosed with SMI are concerned with loneliness, stigma, loss of personal identity, and feeling that others do not hold them in esteem. Accordingly, recovery from these different views is defined as the resolution of different issues, and in fact our use of the terms “objective” and “subjective” to define recovery seems at heart to be referring to whether recovery is defined by an outside person or by the individual experiencing the illness.

In response to the question of whether these views have anything in common, we suggest they share at least two things in common which have far reaching implications. First, both perspectives emphasize that persons with SMI must make decisions about the meaning of the challenges they face in order to recover. If an objective view of recovery is utilized, persons with SMI must first decide that they are in fact ill and could benefit from treatment that may ameliorate symptoms. They might decide, for example, that a certain symptom means that they have an illness for which there may be treatment. If a subjective definition is utilized, to establish a satisfactory quality of life and sense of self as more than a mental patient, persons with SMI must engage in making meaning of their challenges. This requires that meaning making account for unique history, including social connections, ethnic and cultural background, sense of community, personality, etc. In both of these views of recovery, the person in the center is required to make decisions that could lead to recovery, and this includes making meaning of psychiatric challenges. While the nature of these decisions and the requisite meaning making differs, an individual must still have agency and make sense of their experiences.

A second point of agreement between differing models of recovery is that there are many threats to making sense of experiences that accompany SMI. In both perspectives, persons with SMI may struggle to make sense of the objective and subjective elements of recovery in the face of anomalous experiences, demoralization, metacognitive deficits, stigma, trauma, poverty, etc. Providers also face threats to engaging in meaning making with consumers, including anxiety that is often provoked by sitting with someone who may be in a dysregulated or actively psychotic state, heightened institutional concern over safety, and stigmatized beliefs about SMI. Certainly, crises can emerge in which firm action is needed (e.g. acute risk for self-harm). What we are describing here, however, is an insidious process in which clinicians lose or fail to

establish the idea that a unique individual can get to a place of directing personal recovery and that providers' concern over issues of insight or safety lead them to be unwilling to engage in recovery oriented tools that are available to them, such as shared decision making [108,109] and advanced psychiatric directives.

Conceptualizing recovery as involving meaning making in the face of multiple threats has many implications. We will focus on four clinical implications. First, it requires recovery oriented treatments assume that psychotic experiences are human experiences able to be understood [110] and that persons with SMI can form and evolve those meanings. Naturally, symptoms will occur within the course of treatment. Providers must then respond to consumers' unusual thoughts and experiences as potentially meaningful and not something to be treated or extinguished before understanding can be established. Thus, in the course of an interaction, the emergence of an odd belief is understood as possessing any number of potential meanings, consistent with research suggesting that symptoms do not randomly emerge, but can be tied to clear antecedents [111], and can be understood as being linked with emotional pain [112,113]. This requires recovery oriented treatment to cast persons with SMI as active agents in their own recovery in all phases of illness, allowing for people to create their own meanings given their own unique circumstances.

Second, recovery oriented care accordingly requires complex reflections and is likely to be more about process than specific content. Meaning making does not rule out or advantage any specific interventions. Instead, it requires that regardless of content, interventions are used to promote understanding. For example, psychoeducation, case management, or psychotherapy would be recovery oriented if they were stimulating and supporting reflection, that is helping persons with SMI to decide something about their experiences. They would not be recovery

oriented, however, if they were instead telling persons what to think and accept. Thus, the format of treatment may be less important than that it is being jointly used to make meaning.

Third, if making meaning is at issue, the relationship of the provider to the recovering person must be non-hierarchical. What is required of recovery oriented care is dialogue and the rejection of stigma. This is not to deny provider expertise, but that the offer of expertise is in line with the wishes of persons with SMI. Importantly, providers do not need to agree with all that persons with SMI say or believe. Dialogue requires a conversation between two differing perspectives [106] and requires that the therapeutic relationship be dynamic and changing as both client and provider grow in the therapeutic process [114]. It may occur that providers believe that a consumer is not “ready” for recovery and thus make decisions about what is and is not possible for the consumer. This clearly goes against a recovery oriented approach and assumes that providers, due to their expertise or lack of impairment as compared to an individual experiencing SMI, have a more objective view of reality. Such notions must be pushed against and providers must genuinely partner with consumers to assist them in moving toward recovery.

Finally, with meaning making pain may emerge. As persons form an increasingly complex sense of themselves awareness of loss linked with SMI may emerge and persons may struggle to replace comfortable, albeit stigmatized, ideas about themselves. Pain with meaning making may also emerge due to the real implications of stigma and the ways in which people with SMI are marginalized [115], as well as the increased rates of depression and suicide in individuals who experience SMI [116]. Thus, treatment must consider these forms of transformation as complex and unpredictable.

3. Five Year View

Over the next five years, the field awaits further development of conceptualizing meaning making as essential to recovery and recovery-oriented treatment. This requires development of ways to measure recovery that involves persons with SMI first coming to terms with their own experiences and also the perspectives of others. Recovery, as a concept and a treatment orientation, must evolve from forms that consider it the removal of a disease state to views that include living with and making sense of pain while still living a meaningful life. To assist persons in this process, providers and other helpers must be sensitive to issues of power and to not privilege their knowledge as being more valid. To fully embrace the idea of recovery, providers and researchers *must* reject paternalism and abandon the longstanding belief that wellness results from following orders and taking medication. Possibility for recovery has been confirmed empirically, including studies that show wellness over a period of 20 years was not related to taking antipsychotic medication [72,117]. Yet, our field holds onto the idea that treatment providers know how and when people will get better because it is reassuring and reduces the anxiety of both the provider and client. Mental health care cannot be synonymous with seeing clients as clusters of symptoms and attempting to get them to adhere to what we think is best. Undoubtedly, there are catastrophic elements to SMI, and those who experience it suffer profoundly at points in their lives. Embracing recovery does not deny suffering, or reject the notion that providers have expertise to offer their clients. Even amongst subjective definitions of recovery, there must be some consensually valid aspects to a person's recovery, and it must be rooted in the larger community view. For example, someone lacking in relationships, resources, or any fulfilling life roles who denies any problems would not seem to be meaningfully moving toward subjective recovery. At the heart of these conditions, suffering exists and can often be profound. However, available science and contemporary treatments continue to struggle with

how to offer care in a way that balances expertise, acknowledges the profound suffering of those with SMI, and still supports personal choice and mastery in a unique life. The field must embrace heterogeneity of outcomes for those with SMI and fight against professional pessimism about what is possible. Providers and researchers must find ways to concretize the balance between dignity of risk and duty to treat.

Additionally, meaning making at the core of the recovery process calls for efforts to promote and develop integrative treatments that focus on the process of meaning making rather than sole focus on content (i.e., seeing the incorrectness of a delusion). It is the process of making meaning out of experiences that seems to promote agency and plays a pivotal role beyond the distinction of objective and subjective elements, as the process itself seems transformative. Accordingly, therapeutic attempts should be sensitive to the need to make sense of experience and encourage a sense of agency within the client [118]. Notably, a therapeutic alliance in which the therapist and clients work together in an intersubjective space is needed for the client to discover his or her own meaning [106,114]. There are also many areas that may be related to recovery that need to be explored and incorporated into integrative treatments, including neurocognition, metacognition, and social cognition. Similarly, there are elements that seem to be correlates of subjective recovery, such as hope and self-esteem, that are mentioned in the literature but further understanding of their role would be beneficial to inform integrative treatments.

Finally, as the field seeks to understand and promote recovery, it is essential to incorporate individuals who leave treatment or who do not engage in treatment at all. Certainly, the experiences of these individuals offer valuable information to the understanding of the intersection between recovery and the mental health system. People who leave or refuse

treatment are likely a heterogeneous group with a multitude of different outcomes and reasons for electing to not be involved in the mental health system. Understanding the complexity within this group will assist the field in developing a more inclusive and comprehensive conceptualization of paths to recovery and the role of mental health services.

Key Issues

- Recovery continues to be a complex construct in the exploration, conceptualization, and treatment for serious mental illness (SMI) and continues separately discussed as a subjective process or an objective outcome.
- Regardless of how recovery is defined, there is abundant evidence that the outcomes for those with SMI are heterogeneous, and that recovery is the most common outcome.
- Divergent views of what recovery means seem to persist in part due to providers and people with SMI being concerned about different elements of SMI. Providers seem to be concerned with the presence of odd or unusual experiences and psychosocial impairments. Persons with SMI are most concerned with loneliness, stigma, and loss of personal identity.
- Despite the differences inherent in these two conceptualizations of recovery as a process or an outcome, making meaning out of confusing experiences and accepting sense of personal agency seems to be essential in either form of recovery.
- There are several threats to meaning making that providers and persons with SMI must contend with, including symptoms experienced and demoralization that may accompany experiencing a serious mental illness.
- This offers at least four clinical implications for recovery oriented care: i) recovery oriented treatments must assume that psychotic experiences are understandable; ii) recovery oriented care requires complex reflections and must promote reflection and not tell persons with SMI what to think; iii) the relationship between provider and client must create and foster a consultant, non-hierarchical relationship; and iv) recovery oriented care must acknowledge and anticipate pain that comes with the process of recovery.

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****In this manuscript, the authors examine four questions essential to understanding recovery in schizophrenia. Findings suggested that while individuals could easily identify important notions of recovery (i.e. participation in productive activities and a sense of**

agency), the majority of these people were not living in ways consistent with recovery and services promoting recovery (i.e. supported employment are rarely available for them, suggesting that major changes are necessary within mental health care to become truly recovery oriented.

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