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Extrinsic and Intrinsic Factors related to Recovery Process in People with Schizophrenia

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Abstract

The objective of this study was to examine the associations between recovery processes, recovery-oriented practices, and symptom severity in people with schizophrenia attending clinics at Hospital Kuala Lumpur. Psychiatric diagnosis was established using the Mini international neuro-psychiatric interview. Participants completed the RSA, measures of extrinsic enablers of recovery and the RAS, measures of internal recovery characteristics. Clinicians provided ratings using the PANSS, measures of symptom severity, and the M.I.N.I., measures of psychiatric diagnosis. Recovery orientation in individuals with schizophrenia was found to be positively correlated with the presence of recovery-oriented practices in the mental health system and negatively correlated with their symptoms. Recovery-oriented practices in the mental health system as rated by participants was negatively correlated with their symptom severity. The findings of this study suggest that a

recovery-oriented mental health system or milieu is positively associated with the presence of internal recovery values in people with schizophrenia and negatively related to symptom severity.

Introduction:

With a lifetime prevalence rates range from 1.1% to 4% (Bhugra, 2005), schizophrenia is a serious mental illness characterized by hallucinations, delusions, disorganized thought, and disorganized behavior accompanied by impairment in psychosocial functioning (American Psychiatric Association.2013. Diagnostic and statistical manual of mental disorders (5th Ed.). Perceptual and thought disorders can provide interferences in realms of interpersonal functioning, employment, self-care, and ability to live independently (Galletly et al., 2016).

From the beginning of the 20th century, when the term schizophrenia was coined, the common notion prevalent at the time was that schizophrenia was both a neurodevelopmental (i.e. the presence of aberrant genes which manifest later as the brain develops into the clinical presentation of schizophrenia) and neurodegenerative illness (i.e. emotional and environmental factors precipitate noxious neurodegenerative changes in the adolescent or adult brain that results in an inevitably deteriorating course (DeLisi, 2008) (Frese, Knight & Saks, 2009) which results in an inevitably deteriorating course and unfavorable outcome associated with a precocious cognitive decline as seen in schizophrenia (Jablensky, 2007). Remission of symptoms was not commonly anticipated. This did not only make the outlook for schizophrenia bleak but resulted in management approaches that had as its endpoints control of disruptive behavior, symptomatic response, and rarely, remission.

History of Prognostication of Schizophrenia: Remission vs. Recovery

With the advent of the discovery of antipsychotics in the early 1950's (Shen, 1999), the new goal of psychiatric management in schizophrenia was to minimize or ameliorate psychopathology i.e. hallucinations, delusions, abnormal behavior etc. which were collectively referred to as impairment and thus the beginning of the impairment-oriented paradigm. In this paradigm, a person with schizophrenia was said to demonstrate a response to psychiatric management when at least fifty percent of the symptomatology had decreased. Remission is the continuation of the gains made in response phase with mild symptom intensity level, and not influencing an individual's behavior (Andreasen et al., 2005). The symptom criteria are combined with a time threshold of 6 months. While attaining remission is most definitely a desirable milestone in the management of this disorder, remission does not predate recovery from schizophrenia (Leucht & Lasser, 2006) as dysfunction, disability, and discrimination continues to account for the major morbidity of people with schizophrenia (Jablensky, 2000). Unlike other illnesses, be they of physical or mental in nature, the term recovery in schizophrenia continues to be a highly contentious one and is sparingly used by psychiatrists due to the inherent pessimism about the illness. The field of psychiatry dictates that only the strictest of research-based criteria had to be fulfilled before one was pronounced as recovered from schizophrenia. Mental health professionals define recovery as long-term reduction or absence of symptomology along with functional improvement (Hopper, Harrison, Janca & Sartorius, 2007). One such set of criteria required the following: sustained presence (of at least two years) of the following abilities in people diagnosed to have schizophrenia; that they spend at least fifty percent of their time on meaningful educational and/or vocational pursuits; that they could have autonomous control of finances and medication; and that they could have regular contact with their social networks ((Liberman & Kopelowicz, 2002). Recovery was hence dichotomized as an all or nothing endpoint based on the absence or presence of clinical symptomatology, the pronouncement of which lay solely with the treating psychiatrists. No doubt, the inherent conceptual understanding of schizophrenia as a neuro-developmental and/or neuro-degenerative mental illness with an inevitable deteriorating course negatively influences prognostication of this disorder. Emerging evidence from multiple longitudinal studies and meta-analysis of the same however indicates a more optimistic prognosis for schizophrenia. To quote just one, the landmark Vermont longitudinal study which studied 262 patients for 32 years found that at the end of the study period, 50-66% of patients achieved 'considerable improvement or recovery' (Harding, Brooks, Ashikaga, Strauss, & Breier, 1987).

The heterogeneity of Schizophrenia

As opposed to the dictums and assumptions made about it, schizophrenia is neither a homogenous illness with an inevitably deteriorating course (Shepherd, Watt, Falloon, & Smeeton, 1989) nor is it characterized by non-recovery (Harrow, Grossman, Jobe & Herbener, 2005).

Moreover, with respect to episodes of illness, symptomatology, and social impairment, longitudinal data collected over recent decades have convincingly demonstrated that schizophrenia exhibits marked heterogeneity of outcomes in terms of symptoms and functioning (Davidson & McGlashan, 1997). This heterogeneity in outcome is not merely a reflection of the variation of the natural course of the illness (Warner, 2007), dependent on the previously recognized DSM-IV schizophrenia subtypes, or the use of newer antipsychotics. Recent longitudinal cohort studies indicate that the rates of achieving remission in schizophrenia seems much higher than previously thought. What more, people with schizophrenia in remission have corresponding improved outcomes in other domains such as better social and occupational functioning (Eberhard, Levander, & Lindström, 2009). People with schizophrenia in remission are also more likely to favor utilizing medications and have fewer relapses (Emsley, Rabinowitz & Medori, (2007).

With regards to recovery in schizophrenia, the variance in outcomes of schizophrenia is strongly influenced and determined in part by a recovery-oriented approach that promotes an optimum environment (Martens, 2004). An optimum environment is one in which an active treatment approach with the goal of attaining remission is complemented by evidence-based psychotherapy and individualized psychosocial interventions from day one of engagement with psychiatric services. Psychosocial interventions that have proven to be effective include family intervention, coping skills training, emotional regulation and social skills training. In fact, a nation-wide initiative by mental health professionals in the United States to identify empirically supported interventions with proven effectiveness have produced six (6) evidenced-based practices (EBP's) for people with severe mental illness (Harrison et al, 2001). These EBP's are: 1) collaborative psychopharmacology; 2) assertive community treatment; 3) family psychoeducation; 4) supported employment; 5) illness management and recovery skills, and 6) integrated dual disorders treatment.

To summarize this in a cautiously optimistic manner, we now have evidence that the prognosis of schizophrenia can be improved by recognizing and managing the disorder early by providing evidence-based practices that promote recovery. Recovery can best be understood as both an outcome and a process. Corrigan (2006) argues that it is by combining these two concepts that a holistic account of recovery truly emerges.

An impairment or disability -oriented paradigm that has dominated much of the later part of the 20th century has an overt focus on psychopathology and had as its main goal the reduction of impairment. In this paradigm, people with schizophrenia were merely recipients of services instead of active empowered participants of the same. They were told not to be overly optimistic about their chances of living a productive and independent life but instead to have realistic goals. Recovery in schizophrenia was simply not a prognosis (or outcome) entertained except under the occasional but rare strict scrutiny of psychiatrists (Martens, 2004).

As the reader would have probably inferred by now, recovery from schizophrenia was conceptualized by psychiatrists using clinical parameters where the outcome was dichotomized to either recovered or non-recovered. In an apparent contradiction to the psychiatrist-defined recovery, personal accounts of people with schizophrenia in recovery were also beginning to emerge circa three decades ago, describing recovery as a process beyond the mere absence of symptoms and functional impairment and can even take place despite persistent and recurring impairment.

Consumer-defined Recovery: Recovery as a Process Characterized by Salient Features

Beginning in the 1980's, existent literature has challenged the recovered-not recovered dichotomy dictum imposed by psychiatrist by demonstration of the nature of recovery i.e., being a process on a continuum rather than an endpoint (Davidson & Strauss, 1992) (Deegan, 1998). Consumers of psychiatric services report that recovery can and does occur despite the persistence of symptoms and difficulties in functional and social domains. This is what is termed as personal recovery and is best surmised to be a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and roles (Anthony, 1993). It is a way of living a satisfying, hopeful, and contributing life even with limitations

caused by the illness. Recovery involves the development of new meaning and purposes in one's life as one grows beyond the catastrophic effects of mental illness. The recovery process entails the development of cogent attitudes. Such attitudes are positively related to personal responsibility (Andresen, Oades & Caputi, 2003), empowerment (Schrank & Slade, 2007), and hope (Leamy, Bird, Le Boutillier, Williams & Slade, 2011). These facts seemed to be supported by rich empirical data about schizophrenia that has accrued over the recent decades which have somewhat challenged the old paradigm of schizophrenia.

Internal Factors Facilitating the Recovery Process within People with Schizophrenia

Recovery is a process characterized by empowering consumers of psychiatric services with positive attributes, developing one's skills necessary to cope with stigma, managing one's problematic symptomatology, accepting one's personal responsibility for his or her own actions, and keeping one's hope for recovery alive (Andresen, Oades & Caputi, 2003) (Schrank & Slade, 2007). The presence of such characteristics and attitudes within people with schizophrenia is collectively known as intrinsic factors of recovery. Among the many psychometric tools used to measure intrinsic factors of recovery, the Recovery Assessment Scale or RAS (Giffort, Schmook, Woody, Vollendorf & Gervain, 1995) stands out for ease of use. The RAS captures personal recovery characteristics in people with severe mental illness as well as the deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and roles. The RAS has been found to be associated with individual recovery characteristics, the provision of recovery-oriented services as well as good social support (Chang, Heller, Pickett, and Chen, 2013).

External Factors Facilitating the Recovery Process within People with Schizophrenia

As opposed to intrinsic factors of recovery found within people recovering from SMI, recovery from mental illness can also be greatly influenced by extrinsic factors i.e., the recovery orientation of mental health care systems and other systems serving people with serious mental illnesses. Extrinsic factors of recovery are those factors that are in the person's environment that serve to ignite, encourage and bring to fulfilment all the positive factors required towards one's journey to recovery (Shepherd, Boardman, Rinaldi & Roberts, 2014).

Extrinsic factors are typically a supportive family or community, a recovery-oriented treatment milieu, a multidisciplinary team that does not only provide crisis intervention, case management, and rehabilitation services but also promote self-actualization, rights protection, and basic support (Cohen, Cohen, Nemec, Farkas, & Forbess, 1988).

Extrinsic factors also refer to policies and practices of the clinic delivering mental health services (Jacobson & Greenly, 2001) and these contribute to part of what is the optimum environment as discussed above. In it, patients can initiate, pursue, and sustain their life aims. A recovery-oriented healthcare system would encourage patients' active involvement in formulating and deciding their own wellness plans by offering a diversity of treatment options such as individually tailored services (Le Boutillier, Leamy, Bird, Davidson, Williams, & Slade, 2011). In one study examining factors associated with a recovery-oriented program found that individual recovery status was predicted by the provision of recovery-oriented services, low psychiatric symptomatology and good social support (Chang, Heller, Pickett & Chen, 2013). Of equal importance are community-based recovery-oriented services that focus on early intervention and relapse prevention. In the UK, these types of recovery-oriented community-based early intervention and relapse prevention are very effective for both service users and providers in that they are highly accessible to people in crisis or early relapse and as for the service provider and mental health system, avoiding inpatient admissions translates to millions of British £s saved (Knapp et al., 2014).

Assessing consumers' perception of recovery-orientation of the systems serving their needs.

Individual consumer perception of recovery-oriented service was found to be positively correlated with recovery from schizophrenia (Noordsy, Torrey, Mueser, Mead, O'Keefe, & Fox, 2002).

Among the various psychometric tools used to measure extrinsic factors of recovery, the Recovery Self-Assessment Scale (O'Connell, Tondora, Croog, Evans, & Davidson, 2005) is widely used and was chosen for this study. The RSA captures the recovery orientation of the mental health system where people with schizophrenia receive services from. The RSA measures extrinsic recovery-supporting practices in five domains i.e., Life Goals, Involvement, Diversity of Treatment

Options and Choice, and Individually-Tailored Services

The Present Study

With the gradual accumulated hard data on the improvement in prognostication of schizophrenia and determination of encouraging recovery rates along with the discovery of intrinsic recovery processes and external environmental recovery- oriented practices, it was inevitable indeed necessary that a paradigmatic shift occurred which gradually came to be known as the recovery-oriented paradigm.

In line with the Malaysian Ministry of Health Medical Development Division's (2011) policy paper, there is a need to establish and develop rehabilitation and recovery-orientated services. Hence, the present study meets this timely need by examining both intrinsic and extrinsic correlates of symptom severity via a recovery-oriented paradigm. Based on previous findings, we formulated three research hypotheses.

H1: Recovery is positively related to recovery-oriented mental health treatment.
H2: Recovery is negatively related to symptom severity.
H3: Recovery oriented-treatment are negatively related to symptom severity.

Methods

Participants

Participants for this study were drawn from the Malaysian Study of Recovery in People with Schizophrenia (MSRPS). The sample characteristics and the design for MSRPS have been described in previous publications (Tan & Fernandez, 2018). The study was approved by the National Medical Research Register and the Ethics Committee for Research Involving Human Subjects, Universti Putra Malaysia.

This cross-sectional study was conducted at the psychiatric clinic of Hospital Kuala Lumpur. Sample size calculation was based on a previous study by Lloyd, C., King, R., & Moore, L.

Following medical research ethical clearance, we performed data collection from October 2014 to April 2015. Participants aged between 18 and 65 years old were included in the present study if they had diagnosed with schizophrenia based on DSM IV-TR and had consented to participate the study They were selected via systematic random sampling technique. The informed consent procedure was as such. Those patients who were selected via systematic random sampling from the sampling frame (people with schizophrenia attending clinic on that particular day). The researchers (who were either one of the four psychiatrists participating in this study) then invited the potential participant into a consulting room and debriefed them (and their significant others where applicable) as to the nature of the research and invited them to participate. The psychiatrists strongly emphasized the autonomy of participation and that the participants could opt out of the study at any time with no consequence to them. The researchers ensured that all potential participants, irrespective of symptom severity, were only eligible to participate in the study if they fully understood the nature of the study and were able to give a valid informed consent. Psychiatric patients were excluded if they had 1) high suicidal tendency as assessed during intake interview during data collection and 2) had no diagnosis of schizophrenia. Those who were too psychiatrically ill or were unable to understand, receive and carry out instructions were similarly excluded from the study, as were those who for whatever reason declined to participate. Psychiatrists trained in using the Mini-International Neuropsychiatric Interview (M.I.N.I) confirmed the psychiatric diagnosis. To this end, we recruited 118 participants. Gender was equally distributed (age; M = 39.89, SD = 11.377). Of 118 participants, 36.4 % were employed full-time.

Measures

In the present study, three psychological instruments were chosen: The Recovery Self-Assessment (RSA) to assess the presence of extrinsic enablers of recovery, the Recovery Assessment Scale (RAS) to measure internal recovery characteristics and process in people with schizophrenia, and the Positive and Negative Symptoms Scale in Schizophrenia (PANSS) to measure symptom severity.

The Recovery Self-Assessment (RSA) self-report scale (O'Connell, Tondora, Croog, Evans, & Davidson, 2005) (O'Connell, 2005) was used to assess the external measure of recovery from the perspective of service users. The RSA was developed to assess the degree to which mental health care systems and their personnel provided recovery-supporting practices as determined from the perspective of their service users through a 36-item self-report scale. Individual items are rated using the same 5-point Likert scale that ranges from strongly disagree to strongly agree. It consists of five-subscales for five domains of extrinsic recovery process: Life Goals, Involvement, Diversity of Treatment Options and Choice, and Individually-Tailored Services. A total score on the RSA could be obtained. The RSA subscales have demonstrated good reliability (Tan & Fernandez, 2018). Cronbach's alpha for the RSA total score in the present sample was .97.

The intrinsic measure of recovery was assessed using the Recovery Assessment Scale or RAS (Schrank & Slade, 2007), a self-report scale developed to assess internal components of recovery in people with serious mental illness. The RAS has five domain subscales. The subscales are as follows: Personal Confidence and Hope; Willingness to Ask for Help; Goal and Success Orientation; Reliance on Others and finally No Domination by Symptoms. A total score on the RAS could be obtained. Cronbach's alpha for the RSA total score in the present sample was .87.

Participants' scores on symptom severity were obtained via use of the Positive and Negative Symptoms Scale in Schizophrenia (PANSS). The PANSS is an interviewer-rated scale used to measure symptom type and severity in people with schizophrenia (Kay, Fiszbein, & Opler, 1987). The Positive and Negative Scales consists of seven (7) items each and the General Psychopathology Scale consists of 16 items. The minimum score on each item is 1 and the maximum score is 7. Cronbach's alpha estimates for the present study were as follows: Total PANSS (.94), PANSS Positive (.80), PANSS Negative (.92), and PANSS General (.86).

Results

Participants' Perception on Mental Health Services

We used Cohen, Cohen, West, and Aiken's recommendations (2013) to categorize the RSA scores into low, moderate, and high levels. A total of 82.5% participants reported that psychiatric services they received had only low to moderate levels of recovery orientation.

Participants' Recovery Process

We also used Cohen et al.'s recommendations (2013) to categorize the RAS scores into low, moderate, and high levels. When this was done, our findings showed that 15.1, 63.5, and 16.7% of the participants had low, moderate, and high levels of recovery process characteristics respectively.

Participants' Symptom Severity

Following standard procedures for categorization using the PANSS, our findings showed that participants' severity of symptoms was mildly ill.

Correlations among Study Variables

As expected, recovery process of individuals with schizophrenia was positively correlated with recovery-oriented practices ($r = .62$, $p < .05$, Cohen's $d = 1.58$). It is reported that recovery process of individuals with schizophrenia was negatively correlated with their symptom severity ($r = -.55$, $p < .05$, Cohen's $d = 1.32$). Our findings also showed that recovery-oriented practices as rated by participants was negatively correlated with their symptom severity ($r = -.72$, $p < .05$, Cohen's $d = 2.08$).

Discussion

The present study examined intrinsic and extrinsic correlates of symptom severity via a recovery-oriented paradigm. Our findings reported that 82.5% of the participants rated their mental care services were not supportive in their recovery endeavors. In other words, clinic services they received were deemed as not adequately helpful in cultivating hope, overcoming stigma, and connecting to others. An even larger proportion of the respondents (86%) reported only low to

moderate characteristics of personal recovery within themselves. Our sample generally showed a mild level of psychopathology. The low scores on the PANSS is similar to what was found in a cross-sectional study on outpatient population in Asia (Shanker et al, 2014) and is possibly explained by the reasoning that people with schizophrenia treated on an outpatient basis are more likely to be in symptomatic remission as compared to those requiring admission.

Despite mild clinical symptoms of schizophrenia, 86% of these patients reported only low to moderate characteristics of personal recovery within themselves. Findings of this study lends credence to the argument that symptomatic remission is only a means to the end i.e., recovery. Despite being relatively symptom free, the patients in this study still lacked personal confidence, were not optimistic about recovering, set low goals for themselves and lacked a drive to succeed. This is consistent with previous studies which indicate the presence of ongoing functional deficits and residual disability even when symptomatic remission has been reached (Liberman, & Kopelowicz, 2002).

In this study, symptom severity was found to be negatively and significantly correlated to participants' recovery process. These finding replicates that of several other studies done elsewhere (Chang, Heller, Pickett & Chen, 2013), (Norman, Windell, Lynch & Manchanda, 2012) & (Resnick, Rosenheck, Lehman, 2004). Here the authors would like to attempt to postulate a possible explanation for this finding. When psychotic symptoms and thought disorganization are florid in the acute phase of schizophrenia, they cause marked disruption to the patients' ability to think, feel and behave in a normal manner. In this acute state, intrinsic factors of recovery are unlikely to be present in any meaningful degree in the person. However, as demonstrated in the preceding paragraph, even when symptoms are absent or mildly present, intrinsic factors of recovery are still ostensibly lacking.

Given that the recovery orientation of the system was positively correlated to participants' own recovery process, it can be argued that a more supportive recovery-oriented clinical service would help ignite some flicker of hope and facilitate the recovery process. An impairment-oriented mental health service focuses on symptom reduction and remission. While these goals are desirable, such a system takes little account the dysfunction, disability and discrimination faced by people with schizophrenia, what more address the demoralizing impact of mental illness on the personhood, esteem, and social networks. It is no surprise then that psychiatric services have been criticized as being a hindrance (Deegan, 1990) rather than facilitating to recovery. An impairment-oriented mental health service is largely disempowering as patients are recipients of services instead of participating actively in their own recovery, have no autonomy with regards to treatment options, are discouraged from taking risks and not given responsibilities commensurate with their strengths and skills (Tew et al., 2011). Instead of serving as a reservoir of hope, such patients' optimism is tempered with the declaration of prognosis and realistic goals. Relapses and setbacks in management are seen almost exclusively due to patient non-adherence to medications or other self-induced problems.

Practical Implications for Malaysian Mental Health Services

Our recent findings have practical implications for Malaysian health services in three ways. Firstly, we recommend that mental health services in Malaysia make attaining and sustaining symptomatic and functional remission a priority in all people with schizophrenia to prevent chronicity of illness and development of disability. Furthermore, it must be kept in mind that in accordance with recent evidence-based practice principals, the pursuit of symptomatic and functional remission is only a means to the end goal, which is attaining recovery.

Secondly, we recommend the routine use of standardized instruments translated for local needs of external and internal recovery i.e., the RSA and the RAS as part of a new recovery-oriented paradigm that the mental health system must embrace. This is in line with recommendations of a large systematic review encompassing 7431 studies (Slade et al, 2012). A system that is recovery-oriented is immensely therapeutic and conducive to the recovery processes of its service consumers (Avdibegović & Hasanović, 2017)

Thirdly, a recovery-oriented paradigm is one where people with schizophrenia are not merely pathologically impaired individuals whose impairments are deemed the most important target goals. The mental health staff, system and policies acknowledge people with schizophrenia as people with unique strengths, values and interests whose life's goals and pursuits are interrupted by an illness that is known to have potentially debilitating effects on functioning and abilities. A

recovery-oriented paradigm's objectives are not only setting goals to attaining response, remission and recovery but concomitantly to minimize the impact of such an illness on a person's academic, vocational and employment. People with schizophrenia are assisted in planning for their recovery by identifying skills and resources to reach these goals and linking them to them. By doing so, recovery orientation (or rather lack of thereof) can be identified early and appropriate remedial measures can be taken to improve the service delivery of mental health systems as well as address the lack of recovery orientation in people with schizophrenia. A recovery-oriented mental health system goes beyond just remission to encourage and nurture recovery-oriented attitudes and behavior in people with schizophrenia towards their journey towards achieving recovery.

Limitations

The validity of our current findings should be interpreted within the issue of social desirability in that most of the respondents filled up the RSA with the help of the four interviewers who were psychiatrists. In the presence of psychiatrists, the respondents were inclined and had tendency to give positive remarks with regards to the clinical services provided at the clinic. The Hawthorne effect therefore could have resulted in respondents giving more favorable answers about the services and result in artificially higher scores on the RSA. This is also consistent with the theory of social desirability where people on self-report surveys tend to report what they think others may want them to hear and not report what they actually think and feel.

Conclusion

In order for mental health services to be pertinent and effective, it must embrace a recovery-oriented paradigm. In accord to recommendations of international practice guidelines, the Malaysian mental health system can support recovery by promoting community integration and equality, supporting patient-defined recovery and relationship goals, and most critical perhaps is having a clearly defined organizational commitment towards facilitating recovery (Le Boutillier et al., 2011). Clinical remission is not an end to itself but a means to the end of individually tailored recovery plans through the process of psychiatric rehabilitation. This requires a shift away from the erroneous presumption that increasing spending on newer, novel atypical antipsychotics could perhaps alter the course or progression of schizophrenia. As surmised by Liberman and Kopelowisc (2002), if recovery is the desired clinical outcome, management must extend beyond symptomatic remission and include individually tailored psychosocial interventions provided by a recovery-oriented mental health system that helps consumers develop goals and overcome barriers according to their strengths, interests and values. This is consistent with providing of an optimum environment, as postulated by Harrison et al. (2001), to facilitate recovery. As driven by the present findings, we recommend a recovery-oriented paradigm that supports both the intrinsic recovery process and an attempt to promote the provision of an extrinsic ecosystem conducive to recovery.

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