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TITLE:

A BRIEF STUDY ON THE UNDERSTANDING OF RECOVERY
IN SCHIZOPHRENIA

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- B. What is recovery in schizophrenia? A brief introduction**
- C. Is recovery possible?**
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The historical development and the current understanding of the concept of “Recovery” in schizophrenia

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A. Background and Introduction

- The meaning and understanding of the concept of recovery in schizophrenia has long been a terrain of critical negotiation among different disciplines and professions from the last several decades of 20th century to the present day (Davidson, O'Connell, Tondora, Lawless and Evans, 2005: 480).

- Since the time of Kraepelin, schizophrenia has long been viewed as a chronic condition with a very **pessimistic outlook**, recovery from schizophrenia has been considered to be **rare or impossible** (Lieberman *et al*, 2002:266).
- However, at the beginning of the 1980s, the pessimistic view on the prognosis (預後) of schizophrenia has begun to **change**. With a growing number of **follow-up longitudinal studies** on the prognosis of person with schizophrenia demonstrated that many people originally considered by mental health professions to have poor prognosis in the course of illness finally have a very **optimistic outcome** in their later life (Crowson and Wallcraft, 2002: 246; Ballack, 2006: 432).

- Many first hand writings from these consumers/ survivors illustrated the personal accounts of how a person with mental health problem regain the possibilities of overcoming the difficulties of their mental distress and associated effects during their journey to recovery (Ceowson and Wallcraft, 2002: 246).
- These (1) new discoveries in the prognosis(預後) of schizophrenia and the (2) growing waves of consumers/survivors movement in the public open up a new arena for re-defining and re-understanding the term recovery.

- B. What is recovery in schizophrenia? A brief introduction**
- The term recovery appears to have a simple and self-evident meaning in the daily context, conventionally, the term has been used as *free from symptoms* and a *return to healthy stage and wellbeing* (Bellack, 2006: 433), or simply described as *“back to normal”*.(Karban, 2011:24). In fact, within the literature, recovery has been used in a very differentiate and various ways, it could be an *approach, a model, a philosophy, a paradigm, a movement or a version* (Robert and Wolfson, 2006:20 Enabling recovery).

- As the word recovery means different thing to different people and sectors, the diverse usage and understanding of the term recovery across disciplines and professions implies significant differences in assumptions and perceptions (假定和觀念) of the term.
- **“The Scientific Perspective VS The Personal Perspective of Recovery”**

Is recovery possible?

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- Insights from **the new discoveries form recent longitudinal studies** and **personal consumer / survivors accounts** in recovery

1. Discoveries form recent longitudinal studies (歷時性研究)

- Recovery from schizophrenia has been widely documented by a number of longitudinal studies tracing the course of the illness over a long period of time. The growing number of literatures demonstrate *a more positive and optimistic picture of the course of schizophrenia* (Bellack, 2006: 437; Kelly and Gamble, 2005: 247).

- Beginning from the *Vermont Longitudinal* studies, there are about 20 long-term studies has been done (Bellack, 2006: 437).
- The results of these studies report that there are overall 20-70% of participants with research careful diagnosis appear to have a good outcome, with satisfactory reduction of symptoms, good quality of life as well as functioning over extended period of time (Bellack, 2006: 437). The modal percentage with good outcome is in the range of 50 % (Harrison, 2001).

- Bleuler (1965) : 23 years follow-up study / 208 hospitalized individuals in Switzerland were studied
Result : 66% of the participant *recovered completely* and 53% of those had had re-admission recovered.

- Ciompi (1980) : 35-50 years of illness history/ 289 individuals' entire lives
Result : 57% of participants had either *mild disability or had fully recovered* from schizophrenia.

- Huber and his colleagues (1980) : 23 years of illness history / 502 hospitalized individuals in Germany
 - Result : recovery rate was about 57 %. (had either mild disability or had fully recovered from schizophrenia)

 - Ogawa and his colleague (1987) : 21-27 years follow-up study / 140 participants discharged from the Gunma University Hospital in Japan
- Result : 77% of in their study *made full or partial recovery*, no matter some of them had minor psychological difficulties, they were still able to function well socially.

- Harding and his colleagues (1987) : average 32 years of illness history / 269 individuals from the Vermont State Hospital.
Result: 62-65% of participants achieved significant improvement or recovered across multiple domains including symptom severity, work, social relationship and self-care. Among those recovered 45% had no symptoms for two decades and another 23% lost all symptoms of schizophrenia but developed symptoms of other treatable mental disorders (Deegan, 2003:373).

- The International Study of Schizophrenia (Harrison *et al*, 2001) : 15-25 years of illness history / 1,633 participants across 14 culturally diverse areas were investigated.

Result : 48.1% of individual were rated as recovery⁽¹⁾ and 37.8% were rated recovered using a more stringent criterion⁽²⁾

- The Chicago Follow-Up Study (Harrow *et al*, 2005) : a cohort of person with schizophrenia (274 persons) for 15 years were followed/ 5 assessments were conducted.

Result : over 40% of patients with schizophrenia showed 1 or more periods of recovery. 40% of each diagnostic group who were in recovery at the 15-follow up group were not taking antipsychotic.

(1. by M. Bleuler's criteria: employ and resumed formal functioning, not seen as mentally ill by family and no overt psychotic symptoms)
(2) Bleuler's criteria plus Global Assessment Functioning)

Study	Year	Years of follow-up	Setting	Region or country	Results
Bleuler	1965	23 Years	208 hospitalized individuals	Switzerland	<u>66%</u> of the participant <u>recovered completely</u> <u>53%</u> of those had had re-admission recovered
Ciampi	1980	35-50	289 individuals' entire lives	Switzerland	<u>57%</u> of participants had either <u>mild disability or had fully recovered</u> from schizophrenia
Huber and his colleagues	1980	23	502	Germany	recovery rate was about <u>57 %</u> . (had either mild disability or had fully recovered from schizophrenia)
Ogawa and his colleague	1987	21-27	140 participants discharged from Hospital	Japan	<u>77%</u> of in their study <u>made full or partial recovery</u>

Study	Year	Years of follow-up	Setting	Region or country	Results
Harding and his colleagues	1987	average 32 years of illness history	269 individuals from the Vermont State Hospital	The U.S.	<u>62-65%</u> of participants achieved significant improvement or recovered ; Among those recovered <u>45%</u> <i>had no symptoms for two decades</i> and <i>another 23%</i> <i>lost all symptoms</i> of schizophrenia
Harrison <i>et al</i>	2001	15-25 years of illness history	1,633 participants	14 culturally diverse areas	<u>48.1%</u> of individual were rated as recovery; <u>37.8%</u> were rated recovered using a more stringent criterion
The Chicago Follow-Up Study	2005	15 years	274	The U.S.	<u>over 40%</u> of patients with schizophrenia showed <u>1 or more periods of recovery.</u> <u>40%</u> of each diagnostic group who were in recovery at the 15-follow up group were <i>not taking antipsychotic</i>

- One of the findings from the Vermont Longitudinal Research Project was that empirical evidence were found to support that *persons living with psychiatric symptoms were able to enjoy a good life.*
- Within the middle range of outcome, there were subjects in the sample who were considered to be *functioning well*, such as having a job and a good interpersonal relationship with family and friends, but also *still had psychiatric symptoms* like delusions and hallucinations at the same time (Harding *et al*, 1987: 733). These empirical findings suggested *that person with poor clinical outcomes not necessarily go with poor quality of life or vice versa.*

- Implications (含意) from the long-term follow up studies
 1. critically **questioned and challenged** the **pessimistic** Kraepelinian assumption of the prognosis of person with schizophrenia;
 2. clearly shown that individuals with chronic(慢性的) form of schizophrenia and lengthy period of hospitalization are still able to **enjoy a relatively symptom free and well-functioning in their later life.**

2. Consumer / survivors(存活者) accounts in recovery

- Stories, narrations and articles from these consumers/users/survivors suggested that recovery in mental health problem should *not be narrowed down into a cured, removal of symptoms or functioning* but should be a deeper self-understanding, exploration and transformation of their own self.

- Deegan (1996) suggests the term recovery as follows:

“Recovery does not refer to an end product or result. *It does not mean that one is 'cured' or simply stabilized or maintained in the community.* Recovery often involves a transformation of the self wherein one both accepts one's limitation and discovers a new world of possibility... This is the paradox of recovery i.e. that in accepting what we cannot do or be, we begin to discover who we can be and what we can do. *Thus recovery is a process. It is a way of life. It is an attitude and a way of approaching the day's challenges.*”

- Hogan (2003:1469) describes recovery as:
“a process of positive adaptation to illness and disability, linked strongly to self-awareness and a sense of empowerment”

- Turner (2002) points out that recovery is an individualistic process encompasses a wide range of experiences and qualities. Recovery can be ongoing struggles for those who have mental distresses; the process involves : personal growth and learning, taking risks, failing and trying, being able to live independently and others, and being part of the community.

□ Anthony (1993) :

Recovery is described 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 limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.”
(Anthony, 1993: 527)

Scientific Perspective VS Personal Perspective of Recovery

Scientific Perspective:

- focuses on *empirical and scientific investigations* of the traditional dimensions in clinical and social recovery (Robert and Wolfson, 2006:20). This account of recovery is mainly raised by researchers who are willing to develop an operationalized definition and generating factors or domains for recovery in the field of mental health research (Lysake, Roe and Buck, 2010; Liberman and Kopelowicz, 2002; Liberman *et al* 2002).

- recovery is *objectively* measured.
- both symptomatic/functional subjective outcomes are assessed by:
e.g. symptoms, hospitalization, social functioning, community living skills and vocational skills (Jacobson, 2001: 248) , wellbeing and quality of life.

Personal Perspective

- focuses on subjective narrations of the personal and existential dimensions in recovery (Robert and Wolfson, 2006:20). The meaning of recovery is understood in the form of subjective and self-evaluated accounts. This kind of understanding of recovery is based on “lived experience” of a person (Deegan, 1988)

- recovery is understood to be a process with unique and personal experience (Jacobson, 2001: 248).
- By examining these accounts and narrations from person with mental health problems, it is possible to tease out a deeper understanding and dig into the meaning of recovery.

Questions such as: what recovery means to them; what factors aided their recovery; what they perceived as influential to the course of recovery; what they regained during the course of their recovery journey and how they have learnt to accommodate their illness experience.

- **What Scientific Perspective of Recovery is?**
- Recovery is commonly considered to be an “**outcome**”, which “means an endpoint or level of functioning that one achieved and maintains for some period of time” (Bellack, 2006: 433). Thus, **recovery is a cross-sectional reflection of the functional status and may alternate in the course of illness.**
- **lack of golden rule** in defining the term recovery among scientific researches.

- 1. remission of symptoms:
- The Remission in Schizophrenia Working Group
- Positive and Negative Syndrome Scale (PANSS), symptoms remission was operationalized as having at the most to mild level of symptoms for each of the PANSS items* for at least 6 months.

(*delusions, unusual thought content, hallucinations, conceptual disorganization, mannerism and posturing, blunted affect, social withdrawal and lack of spontaneity)

- 2. level of functioning:
- The Vermont Longitudinal Study (Harding *et al*)
- primarily relied on the Global Assessment Scale (GAS) and the Strauss-Carpenter Level of Functioning Scale to assess outcomes.

It adopted a strict criterion for determining good outcome, only those who were scored 61 or above in the GAS would be counted as having a good functioning (0-30= poor, 31-60=fair, 61-100=good functioning) (Harding *et al*, 1987:730) .

“mild in symptoms...or some difficulties in several areas of functioning, but generally functioning pretty well...and most untrained people would not consider him sick.” (Bellack, 2006:433).

- 3. operational definition of recovery
- The 15 years follow-up study conducted by Harrow and his colleagues (2005: 725)
- recovery : required *a 1-year of*
 - (1) absence of major psychotic activities and negative symptoms,
 - (2) adequate social functioning (including paid job or more) and the absence of a very poor social activity level and
 - (3) absence of psychiatric hospitalization.

- Torgalsbøen and Rund (2002)
- recovery as “a reliable diagnosis of schizophrenia at an earlier time but not at present, no psychiatric hospitalizations for at least 5 years and present psychosocial functioning within the ‘normal’ range (scored above 65 on the Global Assessment of Functioning scale)” (Torgalsbøen and Rund, 2002:312).

- **What Personal Perspective of Recovery is?**
- Recovery of mental illness is often a complex **process**. (Anthony, 1993: 527).
- Recovery from mental illness involves much more than from illness itself.
- Anthony (1993: 527) suggests that persons with mental illness have to confront with and *recover from several dimensions of hardships* throughout their recovery process:
“stigma they have incorporated into, iatrogenic effects of treatment, lack of opportunities for self-determination, and even worse, their crushed dreams.”

- Davidson and his colleagues (2005:481) suggests that
- **recovery** does not simply mean a removal of or relief from psychiatric symptoms, **Overcoming the negative effects** of being a mental health patient always become the main theme of the recovery process.

Negative effects: rejections from family, peers and society, financial difficulties (poverty), unemployment, lack of housing, loss of valued social roles and identity, loss of sense of self as an effective social agent, loss of the sense of purpose and direction associated with it and loss of control over their own major life decisions (Davidson *et al*, 2005:481),

- Mueser and his colleagues
- the **recovery** of a person with mental illness, “**social success and personal accomplishment**” (2002:1273). It refers to a number of social and personal matters that a person with mental illness has to confront and deal with during the recovery process.
- **Social and personal matters** : such as the development of self-confidence, of a self-concept beyond the illness, of the enjoyment of the world, of a sense of well-being, hope and optimism.

Scientific	Personal
Empirical, objective and measurable	Experiential, subjective and narrative
① Remission of symptoms	① Process
② Level of functioning (community living skills, vocational skills, wellbeing and quality of life)	② Overcoming the negative effects of being a mental health patient
③ Absence of psychiatric hospitalization	③ Social success and personal accomplishment
	④ Social and personal matters

Conclusion:

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Understanding the meaning of recovery in person with schizophrenia:

1. Recovery does not have a golden rule;
2. Recovery is a concept with both scientific and personal elements;
3. Recovery should not be understood merely in a scientific point of view but instead a humanistic (personal) point of view.

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Thank You