

## **The double hazard in recovery journey: The experiences of UK Chinese users of mental health services**

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### **Citation:**

Tang, L. (2019). The double hazard in recovery journey: The experiences of UK Chinese users of mental health services. *International Journal of Social Psychiatry*, 65(4), 271–278. <https://doi.org/10.1177/0020764019840059>

### **Abstract**

**Background:** The recent interest in recovery from mental health problems has not meaningfully addressed the perspectives of ethnic minorities.

**Aim:** To contribute to the discussion of recovery-oriented service with a study on the experience of Chinese people using UK mental health services.

**Methods:** In-depth life history interviews were carried out with the users. The qualitative data were analysed using thematic analysis.

**Results:** Four themes emerged as hindrances to personal recovery: (1) language difficulty creates hurdles; (2) Diagnostic label is experienced as a double-edged sword; (3) Treatment-related stigma and (dis)empowerment are identified, (4) grievances are found in hospitalisation

**Discussion:** Having mental illness and being an ethnic minority in the UK experienced double hazard in their recovery journey. While the deprivation of agency and the stigma process in the healthcare system hinders their recovery, they are further disadvantaged by their ethnic minority status. Four pointers for service improvement, that apply to Chinese users in the UK and have general implications for users beyond this group, are proposed.

*Keywords: UK Chinese, mental health service, recovery, qualitative, stigma, ethnic minorities*

#### *Funding*

The study is funded by the Overseas Research Students Award, Warwick Postgraduate Research Scholarship and the British Sociological Association Phil Strong Memorial Prize.

## **Introduction**

The recovery movement challenges professional domination and argue for an understanding of recovery as a personal journey with self-defined goals and self-determination to accept or reject certain treatment options (Coleman 2004; Deegan 2007). Scholars have discussed how to transform mental health systems into recovery-oriented models to empower users to live meaningful lives (e.g. Anthony 1993; Slade 2009). However, there is a lack of research that explicitly considers the recovery experience of ethnic minorities. This paper seeks to fill this gap with the experience of Chinese people in the UK. It illustrates factors that facilitate or hinder personal recovery when using mental health services. The discussion considers the central role of agency for recovery and the stigma process in the mental health system, as well as implications for service improvement.

Scholars delineate the multifaceted and contested meanings of recovery. Pilgrim (2008) argues that “recovery” is a polyvalent concept that can mean recovery from symptoms, maladaptive social skills, or iatrogenic professional action. Slade (2009) proposes a paradigm shift from “clinical recovery” to “personal recovery”. Clinical recovery denotes a monolithic vision of recovery as traditionally defined by clinicians that focuses on symptom remission and often on the use of medication to eliminate symptom. To this end, coercive measures to ensure compliance may be used. Underlying clinical recovery is a biomedical model that perpetuates an assumption of psychological pathology and ab/normality. In contrast, based on personal accounts of the users, Slade suggests that the concept of personal recovery denotes the “individually defined and experienced nature” of recovery, a life beyond the role of patient, and an

emphasis on values such as “hope, identity, meaning and personal responsibility” (Slade 2009: 37). He proposes organisational changes in the mental health system from a focus on clinical recovery (which leads to patienthood or illness identity) to personal recovery (which emphasises agency, i.e. to make choice about the direction of their life, leading to positive identity).

Stigma research that emphasises power and structure is useful for understanding the problematics of clinical recovery (Link & Phelan 2001; Corrigan *et al.* 2004; Bonnington & Rose 2014). Link and Phelan (2001) define stigma as a co-occurrence of labelling, stereotyping, separating of “us” from “them”, status loss and discrimination. They argue that it is critical to ask who has the power to separate “us” from “them” and question how the separation is sustained. Corrigan *et al.* (2004) draw attention to the structure of macro institutions and suggest changes are necessary at the policy level (e.g. legislation). Bonnington and Rose (2014) further develop the concept of “structural discrimination”, emphasising how stigma is structured at the nested levels of society. Stigma operates both at the macro-institutional level and in the relations of social roles in daily lives. A focus on agency can illuminate how a stigmatised person negotiates with an illness identity predicated on an “us” vs. “them” separation (Karp 1994). Bonnington and Rose (2014) argue that cultural imperialism exists. This concept, borrowed from Young (1992: 191), refers to the dominant meanings in a society that “render the particular perspectives and point of view of one’s own group invisible at the same time as they stereotype one’s group and mark it out as ‘other’”. People experience powerlessness when identity is constrained, the ability to influence treatment is limited and over-protectiveness is in place. Self-stigma and illness identity develop as a result.

For UK Chinese people, previous studies identified factors hindering their service utilisation: language barrier, a tendency not to identify psychological distress or somatic symptoms in terms of mental illness, and the lack of bilingual mental health professionals (Green *et al.* 2002; Tran *et al.* 2008; Yeung *et al.* 2012). Stigma deters those within the Chinese community from seeking help from mental health services for fear of “losing face” and a reluctance to accept a psychiatric diagnosis (Green *et al.* 2002; Tran *et al.* 2008). However, there is a gap in understanding their experiences of the stigma process inherent in the healthcare system.

Two previous studies explicitly focus on ethnic minority users’ views of recovery in the UK: Southside Partnership/Fanon (2008) on African and African–Caribbean men, and Kalathil *et al.* (2011) on African, African–Caribbean, and South Asian women. Both found that limited treatment options, professional expectations of patient compliance during consultations, and the coercion experienced were antagonistic to the expressed needs of service-users. Stigma in the community was found to hinder recovery. Kalathil *et al.* (2011) argue that individuals’ explanatory frameworks of mental distress, arising from their socio-cultural context, are closely linked to the way they define recovery. They propose to emphasise meaning-making and overcome the social oppression that causes the distress to regain a positive sense of self. This view echoes Bonnington and Rose (2014) in understanding the stigma process in terms of the nested level of society, i.e., within the healthcare system and in the community, as its relation with personal recovery.

This study thus investigates how the healthcare system facilitates or hinders personal recovery. First, it sheds light on the way services impact on an individual’s

exercise of agency. Second, it explores the treatment options available to an individual and whether the treatment was perceived to be conducive to their recovery. Methodology will be explained below.

## **Method**

Data was extracted from a wider project that collect users' narratives of recovery journeys (Author). In-depth life history interviews were conducted to contextualise their recovery experience in their biography and daily life (Elder *et al.* 2003). Purposive sampling was used to reflect the heterogeneity of the Chinese communities. The two recruitment criteria were 1) self-identification as Chinese and 2) a psychiatric diagnosis. The researcher could speak fluent Cantonese, Mandarin, and English. The participants were mainly recruited through introductions by staff and friends at Chinese community centres in Birmingham, Manchester, and London. Chinese community centres were chosen as the primary access points to ensure that the participants could obtain support from the staff, as the process of recounting the recovery journey can be cathartic and distressing (Dickson-Swift *et al.* 2007). Bilingual information sheets and consent forms were given to the participants. The interviews were digitally recorded with permission, and were anonymised.

Twenty-two participants were recruited. Table 1 summarises their demographic characteristics. Recruitment stopped when the researcher became aware of redundancy within the themes in the narratives. Table 2 presents the diagnoses they received.

Table 1: Summary of the characteristics of the participants

Characteristic		Number (percentage)
Gender	Female	13 (59.1%)
	Male	9 (40.9%)
Place of birth	UK	2 (9.1%)
	Mainland China	7 (31.8%)
	Hong Kong	12 (54.5%)
	Vietnam	1 (4.5%)
Number of years in the UK	<10	4 (18.2%)
	11- 20	5 (22.7%)
	21-30	5 (22.7%)
	>31	8 (36.4%)
Age	<30	3 (13.6%)
	31–40	6 (27.3%)
	41–50	4 (18.2%)
	51–60	4 (18.2%)
	61–70	4 (18.2%)
	>71	1 (4.5%)
Language	English only	1 (4.5%)
	Fluent English and Cantonese/Mandarin	9 (40.9%)
	Mandarin/Cantonese only	12 (54.5%)

Level of education	Primary School or below	8 (36.4%)
	Equivalent to UK year 9	2 (9%)
	GCSE or A-level	7 (31.8%)
	Further education	2 (9%)
	Higher education	3 (13.6%)

Table 2: Diagnostic labels received as reported by the participants

<b>Diagnostic label</b>	<b>Number</b>
Schizophrenia/paranoid schizophrenia/hebephrenia	5
Schizo-affective disorder	1
Psychosis with schizophrenic tendency	1
Delusion disorder	1
Manic depression	1
Stress/Stress and anxiety/ Anxiety disorder	3
Mixed anxiety-depressive disorder	1
Depression/ Post-natal depression	5
Unknown (including one reported as “unhappiness”)	7

\*Some participants reported having received more than one diagnosis.



Interview was carried out in two parts to facilitate the iterative process of qualitative inquiry (Srivastava & Hopwood 2009). Participants were first encouraged to recount their stories by answering the open question, “I would like to understand your recovery journey. Can you tell me about it?” In Chinese languages, “recovery” (*Kang Fu/Fu Yuan*) can also mean different things to different people (Tse *et al.* 2012). The researcher did not define the term “recovery” during the interviews, as she wants to find out what recovery meant to them. The participants were encouraged to recount the events leading up to, during, and after the mental health incident or crisis to elicit their sense-making of the journey. The first part of the interview was transcribed verbatim, and was coded according to how agency and personal recovery were supported or deprived. Follow-up questions were then developed to clarify an understanding of the participants’ experiences. Thematic analysis was conducted using the constant comparative method to develop codes and conceptual categories in order to identify themes (Glaser & Strauss 1967).

## **Findings**

Four themes emerged concerning language use, diagnostic label, treatment and hospitalisation.

Language difficulty creates hurdles

Language skill is important in the exercise of agency. The thirteen non-English speaking participants had mixed experiences of interpreting services. Factors reported as hindering their access to interpreting services included a lack of information about services, variable quality of interpreters and worry about gossip by service providers. Nui-xin (female, 51) recalled:

Nui-xin: I ran into an interpreter in a market and she asked me how I had been feeling lately in front of my friends. I felt so embarrassed.

Some preferred to rely on family members to act as interpreters. This arrangement raises the question of whether the users' access to timely services would be compromised if the family member they relied on had other commitments (e.g. full-time work). Moreover, participants said that during risk assessment, family members were prohibited from acting as interpreters. Christy's husband (female, 38) was not allowed to interpret for her during assessments leading to hospitalisation. She perceived this as a sense of distrust from the assessor.

The participants who found interpretation helpful reported meticulous sentence-by-sentence interpretation. Some said that knowing the interpreters beforehand allowed them to feel at ease. Some found it helpful when the interpreters had an understanding of mental health problems and were able to keep calm when and if the user became distressed during the consultation.

Nonetheless, agency to make sense of their distress could still be compromised with the presence of a good interpreter. Subtle details deemed crucial by the users could get lost in translation. Christy considered that this prevented the building of a trusting relationship with the professional:

Christy: Sometimes for private matters, it is difficult to tell the doctor through the interpreter. I feel like I am chatting with the interpreter, not the doctor.

This situation might hinder a process of healing.

#### Diagnostic label as a double-edged sword

Participants reported mixed feelings on the diagnosis they received. Tong (female, 43) was not interested in knowing her diagnosis, as she did not think she was ill and attributed her distress to social factors (constant setbacks in her life such as burglary). She seemed to reject understanding her suffering through a pathologised lens. Nui-xin kept thinking about what her illness “really” was. She did not feel that knowing the diagnosis could give her a satisfactory answer to this question. She reported that two important turning points of her recovery were finding the right medication and finding Christianity, which helped her to clear her feeling of “disturbance by ghosts”. Two different explanatory frameworks based on a biomedical/scientific model and a spiritual model co-exist in Nui-xin’s narrative. The accounts of both Tong and Nui-xin suggest that making sense of their condition in their own non-medicalised terms was important to them.

Some participants were more able to actively manage their conditions once they knew the diagnosis. For example, Wai (female, 31) searched for relevant information online which helped her develop strategies to cope with her emotional highs and lows. Some considered that knowing the diagnosis helped legitimise a state of being that felt strange or unfamiliar.

Zana (female, 31): When I first heard about the diagnosis of depression, I felt relieved as it gave me a way to describe my distress.

However, diagnosis also had a stigmatising effect. Wai contemplated the Chinese translation of the term “manic depression”. The word “manic” can also mean “crazy” in Chinese. Wai worried that she would become crazy and violent one day. Apart from self-stigma, participants reported discrimination by others. Martin (male, 65) said he was divorced by his wife when she found out his diagnosis was “paranoid schizophrenia”. Stigma was no less damaging for those with seemingly less severe informal diagnoses. Li-hui (male, 65) was told that his diagnosis was “stress and anxiety”. The dichotomy of “normal” and “abnormal” ran through his description of medical encounters. For example:

Li-hui: The conversation is not as natural, because we are not normal people.

His “abnormal” identity was related to his doctor’s encouragement to take on the sick role” to make sense of his experience.

Li-hui: When you yell at people, you are abnormal. The doctor asked, ‘Why did you yell at people for no reason?’ He said if you are normal you will not yell at people. Yelling at people is abnormal behaviour.

He felt upset with this “abnormality”. This labelling effect and pathologisation framework seem to lead to a negative self-identity.

Treatment-related stigma and (dis)empowerment

The participants were concerned about the lack of choice in treatment. Medication was the first and often the only treatment offered when they first engaged with mental health services. Some expressed the wish to have more options presented and available to them (e.g. talking therapy). The following findings focus on the two major treatments offered: medication and talking therapy.

Those who found medication helpful considered it useful in maintaining daily life (Rosie, female, 31) and that finding the right medication was the key turning point for recovery (Nui-xin). Some expressed mixed or negative experiences of medication due to adverse effects and withdrawal symptoms. Although Kevin (male, 45) considered that medication helped suppress his delusions, he experienced its iatrogenic effects as disabling:

Kevin: Taking it makes you feel like ... becoming another person. You feel like time flies very slowly... I cannot concentrate. I felt like I was 'woolly headed', deprived of all kinds of emotion.

Some participants experienced their processes of prescription and finding the right medication as a deprivation of agency. Two participants were prescribed psychiatric medication without being told by the doctor that they had a psychiatric condition. Martin went to his GP for severe headache and was prescribed anti-psychotics without explanation. He was angry and reported feeling "tricked" into starting a course of psychiatric medication without being given proper information to make an informed decision. Some actively sought explanations of the medication and its side effects from the doctor, but felt that their concerns were not taken seriously.

Fred (male, 28): I said I don't have big problem now, but I have got this feeling. Then the doctor said, maybe you should take the medication. I said I took it every

day. But I had this feeling. I asked if it was related to the medication. He didn't answer me.

Researcher: Did he talk about ways that you can cope with this feeling?

Fred: He didn't. He just told me to take the medication.

Fred felt frustrated because the doctor did not help him better understand the medication.

The decision to stay on medication was an active process of weighing the pros and cons. For example, Wai said took medicine so that she could take good care of her children. Yet, she was still ambivalent about the idea of taking medication long term and tried to reduce her dosage secretly.

Wai: Taking medication keeps reminding me I am a mental patient.

The medication regime brought an unwanted reminder of patienthood.

Enabling factors such as support from family members or the Chinese community centre staff were found to empower users to make decisions about taking medication. However, professionals' willingness to take the user's experience on board was considered the most important factor:

Nui-xin: I said I couldn't reduce it. He did not believe in me. I followed his instructions. And then I really felt very ill! ...It was a huge psychological threat, reducing the medicine like that. I had been doing fine before that.

Zana: One doctor took the time to investigate the medicines and my experience of side effects with me. I felt respected and supported.

These findings illustrate that the participants did not want to be passive recipients of biomedical treatment regimes.

In terms of talking therapy, five participants who had used Chinese-language counselling from Chinese community centres considered it to be crucial in their recovery. It seemed to compensate for their language capability deprivation and their loose ties in social networks:

Po-guen (female, 58): I have no one to talk to here. My friends in Chinatown ... not that they are not good, but they are more like acquaintances. Not very understanding. They may gossip about me ... The counsellor listened to me. She has patience.

The participants found the self-care skills taught by counsellors helpful for taking control of their wellbeing:

Bei (female, 55): With my anxiety disorder, my counsellor helped me to adjust psychologically. Now I tell myself, 'I will survive. I won't die'.

These participants reported that their self-esteem increased:

Christy: The counsellor helped me to be able to have conversations with other people and to have contact with society again ... at least I feel that I am becoming more like a human being again.

When asked to describe a good therapist, the participants mentioned the following qualities: being skilful, being non-agitating, respecting their wish to retain control and conveying genuine interest in them.

## Grievances in hospitalisation

For the thirteen participants who had been hospitalised, whether hospitalisation contributed to personal recovery was closely linked to the (in)voluntary admission process and hospital life.

Some participants had been hospitalised “voluntarily” because they felt threatened with being sectioned:

Jack: I went in voluntarily, because I don't want to create trouble for myself

Researcher: What do you mean?

Jack: Social workers can be troublesome.

Researcher: What would he do?

Jack: He will section me. And I am not familiar with laws and my rights about sectioning. It could be troublesome.

Such forced “voluntary” admissions are a deprivation of agency rather than a positive action taken by the user.

Most participants who had been involuntarily admitted expressed strong grievances:

Christy: They used power to force me to go to the hospital. I cried every day in the hospital, because I had a deep grievance. Why didn't you give me the right as a patient not to go to the hospital?

The involuntarily nature of their hospitalisation may negatively influence help-seeking behaviour in the future. Although Christy actively sought help with her overwhelming



distress after giving birth, she was only given medication by the emergency team. She did not receive advice about coping with her distressing thoughts. The distress escalated and she was sectioned. While she thought that the hospitalisation helped her bond with the baby, she changed from an active service seeker to a service avoider during her second pregnancy because of the experience of involuntary hospitalisation:

Christy: They just wanted to control me. This only gave me more pressure.

In terms of hospital life, some participants did not find the hospital a place of sanctuary:

Martin: It was frightening. I've never seen such poverty ... It was very basic. Everything was basic. It frightened me.

Helpful aspects of hospitalisation included being given medication that worked, experienced staff, and the chance to build relationships with other inpatients. Relationships among inpatients can foster a sense of community.

## **Discussion**

Although some participants were able to (re)develop capabilities for daily living, nurturing self-esteem and connecting with the community, there are barriers to personal recovery resulting from psychiatric labelling, a pathologisation framework, side effects of medication and the illness identity linked to treatment and hospitalisation. In the following, the central role of agency and the problematic of the stigma process within the healthcare system will be elaborated. Chinese users faced double hazard because of their ethnic minority status. On the one hand, the language barrier and the social

isolation experienced reflect a migration experience common to many ethnic minority groups (Greenhalgh *et al.* 2006; Kalathil *et al.* 2011). On the other hand, their account on the stigmatising effect of particular diagnosis ('manic' is associated with craziness in Chinese language ) and preference to enlist family's help reflect Chinese cultural experience of mental health and help-seeking (Tse and Ng 2014). Implications for services will be discussed.

*First, agency is important for personal recovery.* The findings show that agency was highly valued by the Chinese users, in agreement with recovery literature on the general population and minority ethnic groups, (e.g. Southside Partnership/Fanon 2008; Davidson *et al.* 2009; Kalathil *et al.* 2011). Yet some practices seemed to discourage self-determination and hinder the exercise of agency. This deprivation of agency reflects the problematic of professional dominance in the healthcare system.

Agency is reflected in the quest to make sense of distress and take responsibility to understand the treatments (e.g. Christy, Fred, Nui-xin). The participants who lacked the English language capability were clearly disadvantaged in this respect. Greenhalgh *et al.* (2006) pointed out that the presence of an interpreter in a medical encounter, when handled well, can perform a mediating role and bridge the power imbalance between a user and medical professional. This could explain why some participants valued interpreters who possessed some mental health knowledge and were able to explain the information to them.

The pursuit of agency also means having opportunities to have different treatment options and make informed choices and decisions. The role of family in decision-making is worth noting here. Chinese culture is often associated with collectivism (a sense of responsibility towards family and interdependence). While Tse and Ng (2014)

rightly reminded us that Chinese people can have both individualistic and collectivist value orientations, when family support was welcomed by the participants, it could compensate for their disadvantaged positions as an ethnic minority. Kalathil *et al.* (2011) found that ethnic minority groups with a collectivist orientation welcome services that take their family into account. However, at the point of risk assessment, some participants reported a feeling of distrust because family members were prohibited from acting as interpreters (e.g. Christy). This is where professional dominance was acutely experienced as disempowering. The participants' ability to assert agency was greatly compromised during hospitalisation, when power in the healthcare system was most apparent. Some felt deep grievances about the process of compulsory admission, which could subsequently hinder their recovery. The grievance and wounded agency deterred users from engaging with the services they were entitled to (e.g. Christy).

*Second, the stigma process in the healthcare system hinders personal recovery.* Confirming Bonnington and Rose (2014), stigma was interconnected at the nested level of society. Anticipated stigma in the Chinese community existed and deterred some participants from using community interpreters funded by statutory services. Echoing Julet (2011), receiving a psychiatric diagnosis was a time when the participants experienced the authoritative role of the doctor in pathologising their distress. The stigma process was established at this point. While certain diagnostic labels were experienced as particularly stereotyping (e.g. Wai's "manic depression"), informal labels were also found to lead to the formation of illness identity. This could be explained by the way power operates when the doctor *defines* what behaviour is normal and *persuades* the user to accept this definition (e.g. Li-hui's "stress and anxiety"). This results in the stigma process of separating "us" from "them" (Link and Phelan 2011;

Bonnington and Rose 2014). Changing the signifier of the diagnostic label is not enough to remove the stigma, as long as the ab/normality framework it signifies is unchanged and sustained by power. The symbolic meaning of psychotropic medication also adds to the formation of illness identity (e.g. Wai) (Karp 1994).

The ab/normality framework of pathologisation became dominant in the participants' sense-making of their distress and recovery. In general there was a sense of powerlessness in resisting the diagnosis and the subsequent illness identity. This reflects the cultural imperialism described by Bonnington and Rose (2014). The findings also support the call by Kalathil *et al.* (2011) for practitioners to understand distress as a legitimate response to life circumstances linked to oppressed and disadvantaged positions in society (e.g. Tong). For ethnic minorities, imposing the pathologisation framework could result in experience of double cultural imperialism: invalidation experienced in the healthcare system as well as in society at large.

Based on the above discussion, there are several pointers for service improvement towards personal recovery for Chinese users. First, language capability is crucial for assessing services and articulating their distress on their own terms. Second, users value being able to make sense of their distress within their lifeworld experience. Enabling users to draw on their existing cultural resources to develop a narrative aligned to their lifeworlds (Kleinman 1988), for instance through narrative therapy, might facilitate personal recovery (Roberts 2000).

Third, opportunities for different intervention options were valued by the users. Funding for talking therapy provision, and for training Chinese-speaking counsellors, is vital to making therapy accessible. Alternatives to hospitalisation, such as home treatment, could also be made available to Chinese users. Fourth, the opportunity to

make informed choice was also valued. Clinicians who considered users as partners in treatment decisions and respected their self-determination were experienced as empowering (Deegan, 2007).

While these suggestions may apply to other ethnic minority groups who experience language barriers (e.g. Ida 2007), some of the complaints revealed by the findings apply to *all* users, independent of ethnicity. They reflect the negative aspects of a biomedical regime (clinical recovery and the stigma process). For this reason the learning points suggested by this study have implications for service improvements beyond the Chinese client group.

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