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BRIEF REPORT

Changes in Stigma Experience Among Mental Health Service Users over Time: A Qualitative Study with Focus Groups

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Abstract

Public expenditure on mental health education has grown exponentially in the past two decades. A qualitative study using focus groups was used to explore whether the experience of stigma among 22 mental health service users improved over time. We identified five major themes on changes in social stigma, perceived stigma, and stigma coping. Stigmatizing and discriminatory experiences were still common in workplace, healthcare system, and relational aspects but some participants perceived that there were reductions in social stigma. Participants believed that media portrayal and celebrity effect were important in fostering greater acceptance toward people with mental illness and the importance of family support and stigma resistance for minimizing the harmful impacts of stigma. The findings are important in the future design of public educational and stigma reduction programs.

Keywords Mental health stigma · Antistigma · Stigma-coping · Public attitudes · Stigmatization · Discrimination

Introduction

Many studies have found that the public holds negative attitudes toward mental illness and regards mental health service users as dangerous, and a desire for social distance is common (Parcesepe and Cabassa 2013). Both expectation and actual experience of rejection cause harms to the wellbeing and recovery of people with mental health problems (Mak et al. 2007). Amongst Chinese mental health service users, a sense of guilt and shame is particularly common (Hsiao et al. 2006; Lin 2013). There have been various national campaigns all over the world to promote a socially inclusive attitude toward people with mental health problems (Thornicroft et al. 2016). Some success following these programs in reducing stigmatization and discrimination have been shown using quantitative data (Corker et al. 2016; Evans-Lacko et al. 2014; Hansson et al. 2016; Henderson et al. 2016), but in-depth qualitative data are unavailable.

A recent systematic review of the qualitative data on mental health service users with schizophrenia identified three major themes, including stigma in the healthcare system, relational aspects of stigma encounters in everyday life, and behavioral aspects related to stigma experiences (Mestdagh and Hansen 2014). Other themes mentioned in previous studies include misunderstanding mental health problems as a lack of willpower, overprotection by carers, mistrust toward mental health service users to have children, media portrayal of dangerousness, sense of shame among people with mental illness, and the importance of family support in coping with stigma (González-Torres et al. 2007; Hanafiah and Van Bortel 2015; Lin 2013). To our knowledge, there has been no qualitative study exploring the changes in stigma experience over time from a personal perspective. The aim of this study was to find out how Chinese mental health service users evaluated the changes in social stigma, perceived stigma, and stigma coping. The findings will inform us the areas where further works are needed for reducing the stigmatization toward people with mental illness.

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Method

The present study is the qualitative component of our research on changes in stigma experience among mental health service users in Hong Kong. The quantitative component has been published (Chung et al. 2019). The major findings are that no significant change in perceived stigmatization, rejection experiences, and stigma-coping was found among 109 participants who were interviewed in 2001 and followed-up in 2017. For cross-sectional comparison between participants recruited in 2001 and 2017, there were significant improvements in perceived stigmatization regarding marriage and friendship, but viewpoints on trustworthiness, dangerousness, devaluation, avoidance, and personal failure remained unchanged and no significant difference in rejection experiences and stigma-coping. To obtain an in-depth understanding of changes in stigma experience over the past 16 years, focus groups were arranged to provide opportunities for sharing. All procedures used in this study were reviewed and approved by the local Institutional Review Board.

Participants

The study was conducted at a regional psychiatric outpatient clinic. Among the 193 participants of our baseline survey (Chung and Wong 2004), 109 of them (56.5%) were successfully traced and re-assessed in 2017. We asked the 109 participants their interest to join our focus groups. Participation was voluntary and a travel allowance of HK$100 (£10 or UK$13) was provided. The sample for the qualitative study was obtained by purposive sampling but not based on random sampling. We compared the 22 focus group participants with the 87 non-participants and found that there was no significant difference in age, gender, marital status, occupation, living condition, psychiatric diagnosis, age of onset of mental illness, number of previous hospitalization and the total scores on perceived stigmatization, rejection experiences, and stigma-coping (all $p > 0.05$, unpaired t or Chi square test). The only difference between the two groups was that focus group participants had higher educational level (mean ± SD = 12.7 ± 2.6 years) than the non-participants (11.2 ± 3.3 years) (unpaired $t = 2.0$, $df = 107$, $p = 0.045$).

Procedures

Focus groups were held in a quiet room. To ensure group dynamics, each group was planned for six to eight participants, moderated by two researchers, and lasted for about 1.5 h. One researcher was responsible for guiding the discussion and encouraging participation. The other researcher took notes and kept track of time. Both researchers had undergraduate degree in psychology and did not actively participate in group discussion. All discussions were audio-recorded for further analysis. In order to protect participants' privacy, all recording files were encrypted and password protected. The study would be stopped when thematic saturation was achieved, with no new themes or ideas emerged.

Upon arrival, participants were introduced the study background and procedure and were free to ask any questions regarding the study. The discussion was in participants' mother tongue, Cantonese, and consisted of a list of open-ended questions on participants' views regarding the changes in perceived stigmatization, rejection experiences, and stigma-coping over the past 16 years. Before proceeding to the next question, the researcher summarized the major points and checked whether participants had further ideas to add. The question route was pilot-tested amongst 10 mental health service users for its comprehensiveness and was revised based on their feedback.

Data Analysis

The data was analyzed based on the grounded theory approach, which is an approach of developing theories inductively from examination of data instead of deducing theory through hypothesis testing (Payne 2007). A qualitative analysis software NVivo version 11 was used to code and group data. Without predefined hypotheses or theoretical framework, the author (WC) replayed the focus group audiotapes and transcribed the conversation verbatim. The texts were fragmented into meaningful units and each unit was labeled with an inductive code. Constant comparison among codes was applied to refine the coding frame and to group codes pertaining to the same phenomena as conceptual categories. Focus group meeting and data analysis proceeded simultaneously so that the researcher was able to assess whether thematic saturation was achieved. The development of the coding frame ceased when thematic saturation was reached. Two other researchers independently listened to the audiotapes to check that all meaningful contents were extracted. A framework of themes was developed after repeated discussion among research team members. Data coding was conducted in Cantonese. Quotes presented in this paper were translated from Cantonese into English by the author (WC and KC). When data analysis was completed, two to three quotes from each theme were drawn and randomly arranged. An independent researcher was able to correctly assign the quotes into their corresponding themes.

Results

Sample Characteristics

A total of 22 participants formed 4 focus groups. The mean age was 55.18 years, 68.2% were female, and 59.1% were single. The mean duration of illness was 28.5 years; 5 of the 22 participants (22.7%) were diagnosed as schizophrenia, 9 (40.9%) as bipolar disorder, 4 (18.2%) as major depressive disorder, and 4 (18.2%) as anxiety disorder. After repeated reading of the transcripts and revision of framework, five main themes were developed.

Theme A: Changes in Public Stigma: Two Sides' Viewpoints

This theme focuses on participants' contrasting opinion regarding public stigma in the past decade. Most participants considered public stigma had not changed over the past 16 years and that the public was just play-acting to be nice to people with mental illness. A minority of the participants reported that there was greater acceptance toward people with mental health problems and that public education and celebrity effect was the driving force behind the improvements in public stigma.

> I think there is no reduction in stigma. Maybe people just do not show it explicitly, but deep inside they still want to distance from us … the situation has not changed at all. (Participant no. 6)
> Whenever there are violent incidents happened, people will immediately relate the events to mental illness or some form of mental disturbance. (Participant no. 18)
> My psychiatrist told me that there was no difference between my illness and a person with stomachache or high blood pressure … However, people kept thinking that mental illness was terrifying … They would stay away from us if they knew we had mental illness … they definitely would … (Participant no. 16)
> People now kept using the word "integration" … but have they ever accepted us? … It was just some form of "packaging"…. the "packaging" by the government was good. (Participant no. 15)
> Even though the public does not seem to discriminate against us, they still think we are less capable. So they would exclude us … (Participant no. 10)
> The news is all negative about us. There is nothing good … that is why people won't accept us … Even worse, the bad news is shown every few weeks, brainwashing people that mental illness is associated with violence … they won't show how we have recovered and re-integrated in the society… (Participant no. 4)
> Doctors appeared on TV programs and talked about causes of mental illness … e.g., depression is due to work stress or other problems, and is not crazy. People can have a better understanding … people are more likely to accept us. (Participant no. 6)
> … maybe there are public campaigns or celebrity effect … Some celebrities said they have depression and other illnesses … it is why people are more ready to accept mental illness. (Participant no. 11)
> The situation has improved to a certain extent, but I don't know whether it is because of the mass media … I think the mass media is really important … (Participant no. 11)

Theme B: Changes in Self-Stigma: From Hate to Acceptance

Participants reported how the society's rejection and negative attitudes affected their views toward themselves and how their family helped them overcoming self-stigma.

> I have given up on myself before. I laid on bed, slept day and night, and went to washroom only … because the society did not accept me. I worked hard, but was still being fired. My students played tricks on me … bullying me. It is not students being bullied by teachers, but teachers being bullied by students… (Participant no. 15)
> Whenever there were negative comments about me, my mood would be affected. I was not a person with high self-esteem and how others thought about me had great influence on me … (Participant no. 22)
> Yes, I had given up on myself before … but now I won't … I have support from others, and I know they are my best friends. (Participant no. 15)
> How your neighbors and other people treated you does not actually matter. When you go home and are given a warm welcome, it does not matter how others think about you. Family's support is really important. (Participant no. 15)
> There is something nice about my family. Although I have mental illness, they won't treat me differently. They treat me as a normal person. I think this is exactly what a psychiatric patient needs. (Participant no. 22)

Theme C: Unaffected by Stigmatization

There are a variety of ways mental health service users cope with public stigma. Some participants did not experience any self-stigma and were not influenced by negative attitudes toward people with mental illness. Rather than feeling sad and experiencing self-stigma, some participants expressed anger when they encountered unfair treatment and discrimination. A minority of the participants thought they had personal growth over the past decades and could empower others through their experience. Some participants learnt to understand the public's reactions toward mental health problems.

> (Have you been affected by others' prejudice against you?) I won't … I have confidence in my own ability. I just feel it's unfair … they cannot label me because of my illness. (Participant no. 8)
>
> We made jokes about news on newspaper … my friend told us that: "There is an insane person chopping people!" Another friend then said "don't you dare to offend her (the participant) … there is no need to go to jail for killing you!" It was fine for me, it was just a joke and did not bother me at all. I accepted myself and my illness. How others think about me does not bother me at all. (Participant no. 17)
>
> If someone discriminates against me, I will try to improve myself. I cannot control how others think about me, so I have to try my best to perform well and it will be ok. (Participant no. 10)
>
> I will use my own experience to share with someone who has the same problem. I think I have a strong persuasive power … and I have tried helping others before. (Participant no. 17)
>
> I think the influence of discrimination on me is less than before … because I have adapted to it. (Participant no. 13)
>
> Frankly speaking, if you haven't lived with a person with mental illness, it is understandable that you have fear. (Participant no. 17)

Theme D: Changes in Rejection Experience: Two Sides' Viewpoints

Most of the focus group participants mentioned that they had experienced rejections. When asked if there were any improvements in the past 16 years, there were contrasting viewpoints. Some participants still had unpleasant experiences. They encountered rejections at their workplace, at the interpersonal level, and during their encounters with healthcare professionals. The unfair treatments include rejections by employers and colleagues, being turned down at job interview, being given less responsibility and lower salary, and being fired from work. However, a small proportion of the participants reported that the society had improved and they experienced less rejections than before.

> If you let others know your illness, you will definitely lose your job … even if your boss doesn't fire you, the criticisms from your colleagues make you feel like you have to leave … every morning when I wake up for work, I feel so stressful … (Participant no. 7)
>
> The government has set up a minimum wage, but our salary system is different and can be lower than the minimum wage. I think this is discrimination … why can't we have the same salary like other workers? (Participant no. 16)
>
> My employer would allocate less important work to me … more simple and repetitive kind of work … and would not let me try some important positions. (Participant no. 8)
>
> The last time when I had a relapse, my family did not allow me to go back home … they told the doctor that they did not want me back, and listed out what I had done wrong … they did not visit me for 8 months … originally I could be discharged after 1 month but I stayed in hospital for 8 months because I had nowhere to go … (Participant no. 9)
>
> My friends stay away from me, thinking that I am irrational. They don't accept me and stay away from me. (Participant no. 8)
>
> In the place where I lived, everyone knew that I had mental illness … When the kids saw me, they would ask me whether I was crazy. (Participant no. 14)
>
> Every time when I had to see a doctor for some health problems, they would simply say I was nervous… or I was receiving psychiatric treatment… I asked myself why there was a relation between my health problems and my psychiatric history. I didn't know whether it was discrimination or they had a wrong impression about me … they just did not arrange enough check-up on my problems. (Participant no. 11)
>
> Discrimination seems to have improved. I am quite negative in the past … whenever people know that I have mental illness, they will think I have a big problem. In the past 10 years, some employers have accepted and hired me… they understand that I have work ability. (Participant no. 9)
>
> In the recent 1-2 years, there are some improvements in doctors' attitudes. They have less misconception about us. Perhaps it is because the younger generation has better understanding about us … (Participant no. 11)
>
> A lot of my friends know that I am seeing a psychiatrist and they seem not to be bothered…. at least they do not appear to be surprised. (Participant no. 17)

Theme E: Changes in Coping Strategies

Most participants agreed that they used secrecy to avoid discrimination and rejection but some participants mentioned that they dealt with stigma by ignoring the negative comments and learned to be more flexible in coping.

> … I would not tell others that I have mental problems because stigma still exists … some people may feel scared, so I've been hiding this secret and do not tell others that I have mental problems. (Participant no. 5)
>
> I don't want to ruin my mood because of that … just laugh it off and pretend nothing has happened. (Participant no. 5)
>
> I just laugh it off and leave, considering that they have little understanding about this issue. (Participant no. 12)
>
> I think my coping depends on the attitude of that person. If he is open-minded, of course I will try to explain … however, if I find that he is stubborn, I won't try to explain. I don't want to make things worse… (Participant no. 11)

Discussion

This is the first qualitative study on mental health service users' personal experience of stigma over time. There are divided views about improvements in public stigma and rejection experiences. A small proportion of participants perceived that there were improvements in attitudes in the general public and among healthcare professionals and there were more employment opportunities, but others had reservation about the improvements and felt that the public was just play-acting to be receptive and they were given lower salary and less responsibility due to their history of mental illness. Participants said that they had learnt to be indifferent toward stigmatizing comments and became more flexible in stigma coping. They considered family support as one the factors helping them to cope with stigma. In line with our quantitative study (Chung et al. 2019) and data in the West (Corker et al. 2016; Evans-Lacko et al. 2014; Hansson et al. 2016; Henderson et al. 2016), the overall finding is that there are only slight improvements in public attitudes toward people with mental health problems over the past two decades and that stigmatization and rejection are still common.

Focus group participants expressed concern that the public still holds a strong belief that people with mental health problems are violent, weird, and less capable. Participants believed that media portrayal and celebrity effect were important in fostering greater acceptance toward people with mental illness. A recent meta-analysis showed that mass media interventions may reduce prejudice, but the conclusion was limited by the quality of the evidence (Clement et al. 2013). Another review found that anti-stigma interventions on mass media professionals and guidelines on media reporting had some positive effects on reporting style (Maiorano et al. 2017). Our findings and the literature seem to support that mass media interventions are promising approaches for improving public attitudes toward people with mental illness. Studies showed that media coverage of celebrities with mental health problems had correlations with discussion of mental health topics in social media and knowledge and help-seeking for mental health problems (Lee 2018; Leung 2019). The findings are in line with the impression of our participants that sharing by credible celebrities of their experience of mental illness is able to improve social stigma.

Another topic covered by our participants is the importance of family support in reducing the impact of stigma. Although Hong Kong is a metropolitan city, its Chinese root remains relevant in shaping how Hong Kong Chinese and their families react to mental health problems. Chinese mental health service users are more likely to be bothered by their failure to fulfill familial obligations and a sense of guilt and shame is common (Hsiao et al. 2006). In addition, Chinese patients may view themselves as bad sons or daughters while their family members may view them as a burden because they fail to achieve success and could not live up to the values of filial piety. Findings from previous studies are in line with that family support is a major factor that can reduce internalized stigma and improve mental health outcomes (Korkmaz and Küçük 2016; Moses 2014).

Focus group participants mentioned that they have learnt to ignore the negative comments about mental illness, acknowledge the presence of social stigma, and become more flexible in stigma-coping. The coping strategies used by focus group participants are similar to the concept of stigma resistance, which is used to describe the capacity to resist, counteract, or otherwise remain unaffected by mental illness stigmatization. A recent meta-analysis has shown that greater stigma resistance is associated with reduced internalized stigma, greater hope, self-efficacy and self-esteem, better recovery, and improved quality of life (Firmin et al. 2016). However, most studies are cross-sectional in design, hence it is difficult to delineate the direction of the relationship and whether the relationship is moderated by clinical factors, such as duration of illness. Focus group participants reported that their resistance to stigma improved with time, suggesting that stigma resistance may be a process of personal growth. Further studies should incorporate the concept of stigma resistance in the design of stigma reduction programs.

The present study has several strengths and limitations. The heterogeneous sample allows us to explore individuals of different sociodemographic background and psychiatric diagnosis. Our focus group participants have a long history of lived experience of mental illness; hence their experiences are great sharing beneficial to healthcare professionals and other mental health service users. One of the major limitations is the small sample size. Although thematic saturation was attained with the forth focus group, it may be better to conduct a few more focus groups to confirm that there are no new themes and concepts. Another limitation is that the personal account about changes in stigma over time is retrospective and subjected to recall bias.

The current study provides an overview of the personal experience of stigma over time amongst mental health service users. Our findings suggest that there may be slight improvement in stigma experience over the past two decades, but discrimination and rejection are still common. Further works are needed to be done to improve the public's attitudes and acceptance of people with mental health problems.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the Ethical Standards of the Institutional and/or National Research Committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Ethical Committee Permission Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster Reference Number UW 16-459.

Informed Consent Informed consent was obtained from all participants included in the study.

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