Original Research

Stigma as Perceived and Experienced by People with Mental Illnesses who Receive Compulsory Community Treatment

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Abstract

Purpose: This study explored how stigma was perceived and experienced by people with mental illnesses who were legally required to use mental health services while living in the community.

Method: Interviews were conducted with 91 people with mental illnesses who were receiving compulsory community mental health treatment in British Columbia, Canada. An inductive thematic analytic framework was used to identify predominant themes and recurring patterns in the qualitative data.

Results: Participants’ narratives centered around six primary themes: (a) compulsory treatment; (b) feeling/being knocked down; (c) public (mis)understanding; (d) social identity/location; (e) social disadvantage; and (f) passing-managing-overcoming. Compulsory community treatment was entangled with a myriad of other stigma-producing factors associated with the direct effects of mental illnesses and social disadvantage.

Conclusion: Compulsory community mental health treatment is not the predominant issue that produces stigma among people with mental illnesses, but it may contribute to such experiences by creating situations where people are likely to feel powerless, devalued, and oppressed.

Keywords: compulsory treatment, mental illness, qualitative, stigma

Introduction

Over the past decade, there has been a rapid expansion of research and theory on health-related stigma, defined as a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group (Weiss, Ramakrishna & Somma, 2006, p. 280). The stigma associated with mental illnesses has detrimental effects that are acute and far-reaching, contributing to poorer self-esteem, hopelessness, and poorer treatment adherence (Livingston & Boyd, 2010).

Alongside efforts to reduce stigma-related barriers and promote social inclusion for people with mental illnesses, there has been an expansion of mental health legislation that restricts the rights and freedoms of those who live with severe, persistent mental illnesses (Dawson, Romans, Gibbs & Ratter, 2003; Trueman, 2003; O’Reilly, 2004; Wales & Hiday, 2006; Patel, 2008; Kaiser, 2009). Compulsory community treatment is one example of a legal obligation imposed by the State that requires people with mental illnesses to comply with conditions of treatment and supervision while living in the community (Trueman, 2003; Winick, 2003). In British Columbia (BC), Canada, compulsory community mental health treatment is comprised of extended leave and conditional discharge. An extended leave is a legal option under the civil Mental Health Act of
BC that enables a psychiatric hospital to place conditions on a person who is civilly committed in order to evaluate their ability to function as they make the transition into the community (Gray & O’Reilly, 2005). A conditional discharge operates similarly; however, it is ordered through the Criminal Code of Canada (section 672) for individuals with mental illnesses who are adjudicated ‘Not Criminally Responsible on account of Mental Disorder’ (NCRMD). Under both forms of compulsory community treatment, people with mental illnesses remain under the control and supervision of a mental health professional and are legally required to comply with a prescribed plan of treatment and support while living in the community. Failure to comply with these conditions results in involuntary detention – often by the police – and hospitalization.

Several qualitative studies have investigated how people subjectively perceive and experience compulsory mental health services. A study that examined multiple perspectives of community treatment orders in Canada found that, among 14 individuals who received these services, experiences of coercion were prevalent; however, opinions about community treatment orders ranged from anger and ambivalence to appreciation (O’Reilly, Keegan, Corring, Shirkhande & Natarajan, 2006). Similarly, a British study of twenty mental health service users revealed a diversity of perceptions and experiences concerning supervised discharge orders and guardianship (Canvin, Bartlett & Pinfold, 2002). Within this study, individuals often held contradictory attitudes and beliefs about receiving compulsory community treatment. These findings are echoed in another study of 42 service users under community treatment orders in New Zealand in which the researchers concluded that: The [community treatment order] appears to ‘save lives’ but can be like a ‘rope’, where service users are ‘held back and kept under rule’ (Gibbs, Dawson & Mullen, 2006, p. 1096).

To date, qualitative research has not specifically focused on how stigma is perceived and experienced by people with mental illnesses who receive compulsory community treatment. This article reports on the qualitative component of a mixed-methods study. The quantitative results of this study, and qualitative findings related to the effects of the ‘forensic’ label on mental health service users’ experiences, have been published elsewhere (Livingston, Rossiter & Verdun-Jones, 2011). The data presented here reveal the themes that were identified as being important and meaningful to the experiences of stigma among people in the community who were legally required to use mental health services. Of particular interest was learning how people discussed compulsory community mental health treatment in the context of stigma.

Methods

Recruitment

Purposive sampling was used to recruit study participants from hospitals and community clinics throughout BC. Recruitment advertisements were posted in waiting rooms and mental health service providers were asked to distribute informational pamphlets to people who met the study’s inclusion criteria. Participants had to be: (a) certified under the BC Mental Health Act or adjudicated NCRMD under the Criminal Code of Canada; (b) receiving compulsory treatment in the community for at least 30 days; (c) 18–65 years of age; and (d) diagnosed with either schizophrenia-spectrum disorder, other psychotic disorder, or bipolar disorder by their treating psychiatrist. The research protocol was approved by the Research Ethics Board at Simon Fraser University and written informed consent was obtained from all study participants.

Materials and Procedures

Data were gathered through self-report, in-person interviews. Each interview was conducted by either the first or second author and lasted for approximately 90 min. The interview guide included the Inventory of Stigmatizing Experiences (Stuart, Milev & Koller, 2005), which contains 18 open-ended questions about lifetime experiences of mental illness-related stigma. The Inventory was used to elicit qualitative narratives by asking participants to describe their experiences in their own words. For example, one question asked participants to indicate whether they felt that they had ever been treated unfairly or ever had their rights denied because of their mental illness. Those who answered ‘yes’ were then asked to describe relevant experiences, thoughts, and feelings. Interviews were not audio recorded; however, the interviewers took detailed field notes during and after each interview, reflecting on participants’ narratives and capturing their experiences as accurately as possible.

Qualitative Analysis

Qualitative data were analyzed by the principal author using an inductive thematic analytic framework to identify predominant themes and recurring patterns (Strauss & Corbin, 1990; Braun & Clarke, 2006). The analysis was conducted in three phases. First, using open coding and line-by-line analysis, the qualitative text was fractured into over 100 discrete codes that reflected what a participant had said within a particular line of text. Second, the initial codes were combined based on similarities and differences,
and were collapsed into 16 unique codes through a recursive process of moving back and forth between the codes and original text. Third, the 16 codes were sorted, categorized, and refined into six overarching themes. Each theme represents the sentiments of several participants and captures key ideas and patterns that were considered to be important and meaningful to the research questions.

**Results**

*Participant Characteristics*

Ninety-one participants were interviewed. Three quarters of participants were men (n=69, 76%), almost two-thirds were white (n=56, 62%), and most were diagnosed with schizophrenia-spectrum disorders (n=76, 84%). Demographic characteristics are summarized in Table 1.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Total (n=91)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>69</td>
</tr>
<tr>
<td>Female</td>
<td>22</td>
</tr>
<tr>
<td><strong>Age in Years, Mean (SD)</strong></td>
<td>91 39.0 (11.6)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>56 62%</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>9 10%</td>
</tr>
<tr>
<td>Asian</td>
<td>6 7%</td>
</tr>
<tr>
<td>East indian</td>
<td>5 6%</td>
</tr>
<tr>
<td>Other</td>
<td>15 16%</td>
</tr>
<tr>
<td><strong>Relationship Status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>57 63%</td>
</tr>
<tr>
<td>Not married</td>
<td>34 37%</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>22 24%</td>
</tr>
<tr>
<td>Not employed</td>
<td>69 76%</td>
</tr>
<tr>
<td><strong>On income Assistance</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>81 89%</td>
</tr>
<tr>
<td>No</td>
<td>10 11%</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
</tr>
<tr>
<td>Did not complete high school/GED</td>
<td>40 44%</td>
</tr>
<tr>
<td>Completed high school/GED</td>
<td>51 56%</td>
</tr>
<tr>
<td><strong>History</strong></td>
<td></td>
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<tr>
<td>Of homelessness</td>
<td>44 48%</td>
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<tr>
<td>Of incarceration</td>
<td>72 79%</td>
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<tr>
<td><strong>Primary Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>53 58%</td>
</tr>
<tr>
<td>Schizoaffective disorder</td>
<td>23 25%</td>
</tr>
<tr>
<td>Other psychotic disorder</td>
<td>10 11%</td>
</tr>
<tr>
<td>Bipolar disorder</td>
<td>5 6%</td>
</tr>
<tr>
<td><strong>Substance Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>49 54%</td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>Years with Mental Illness, Mean (SD)</strong></td>
<td>91 12.9 (10.8)</td>
</tr>
</tbody>
</table>

**Compulsory Treatment**

The first theme reflects the tension between care and control, and the power differentials that participants reported experiencing while receiving compulsory mental health treatment. In the context of stigma, participants talked about their experiences of being involuntarily hospitalized and detained:

They [the staff] didn’t treat you as a human being. The staff ignored what you had to say regardless of what you said . . . you were considered just mentally ill. My rights and freedoms have been denied ever since I got involved with mental health. My basic humanity was denied at the psychiatric hospital . . . Didn’t leave much room for recovery.

A number of participants indicated that they were forced to stay in the hospital for too long, which they felt was unfair:

I’ve been in hospital for 10 years, and other people with similar crimes have been released from [hospital] sooner.

The psychiatrists keep me trapped . . . keep me confined.

Moreover, being on a compulsory treatment order, which may result in being repeatedly removed from the community on account of psychiatric hospitalizations, interrupted participants’ lives including maintaining stability with relationships, housing, and employment:

[Compulsory community treatment] puts your life on hold.

If I wasn’t sent back to hospital last time, I would have been further ahead.

How many people do they arrest if they have diabetes?

Participants also reflected on how they felt unfairly treated, or disrespected, by mental health service providers, particularly in the course of being civilly committed. Of primary concern was the amount of power wielded by mental health staff in relation to treatment decisions:

I want to tell him [the psychiatrist] to go to damn hell. Who is he to tell me how much medication I take? They force pills on you . . . I need people to stop telling me what to do!

I felt powerless for ten years, and treated like I couldn’t make decisions for myself.

It would be better if I could have the final say on the treatment I receive – that would make me feel better mentally.
Furthermore, some participants felt that there was a limited range of treatment options, and that voicing their concerns about a prescribed treatment plan would result in further medication or disciplinary measures:

I understand that I need meds to control the psychosis but I feel over-medicated. I’m forced to take medications that screw me up. I suffer from panic attacks from the meds and it slurred my speech.

You don’t get much help and support, other than drugs.

You weren’t allowed to speak up for yourself without just being considered agitated. They would medicate and side room you when you raised your voice and concerns.

A few participants spoke about the challenges of wanting to get well but being reluctant to disclose active symptoms to their treatment team because they might be forced to take higher doses of psychiatric medication: There are consequences for disclosing symptoms to the treatment team.

Overall, the profound narratives contained within this theme reflect participants’ feelings of powerless – including the perception that their personal autonomy had been constrained, and that their rights and freedoms had been curtailed.

Feeling/Being Knocked Down

Many participants reported that, on account of their illness, they had been mistreated by others and that this, in turn, had adversely affected their feelings about themselves. A common experience for participants was being treated as if they were incompetent or incapable because of their mental illness:

They [the public] think you’re not capable because you’re not a normal person like everyone else . . . they think you’re inferior just because you’re a little bit off your rocker.

If you decide to cook dinner, staff will tell you to pick something easier.

At times, stigma was experienced directly, by being called derogatory names by educated professionals, whereas other times, participants experienced stigmatizing attitudes more indirectly during interactions with criminal justice and health professionals, and their own families:

People think you’re not credible, you have poor judgment. It destroys your personal reputation . . . the cops won’t believe you if you report a crime . . . you’re blamed and taken advantage of.

Psychiatrists in the hospital don’t believe what you have to say and keep you in hospital for a long time.

My brother understands mental illness, but my sister thinks mental illness is a disgrace to the family. My family phones me but they don’t come to see me . . . they’re disgraced and think that I’m crazy and stupid.

My parents treat me like a baby boy now.

Participants described feeling hopeless, worthless, and doubtful of themselves, which, for some, compounded the problems of mental illness:

You think less of yourself, so you’re not as open as you could be.

It makes you want to give up . . . don’t want that on top of your mental illness.

The narratives contained in this theme illustrate how the negative reactions of family, friends, and professionals to the experiences and expressions of people with mental illnesses can adversely affect their self-esteem and sense of self-worth.

Public (Mis)Understanding

A third theme concerned social stereotypes and public ignorance about mental illness. Participants’ narratives contained several references to the public’s fear of mental illness, which was thought to be partly produced by the fact that mental illnesses are unknown to, or poorly understood, by the public:

People are afraid of what they don’t understand.

They’re not putting themselves in their [people with mental illnesses] shoes – so they don’t understand. They don’t know how we feel. If they did, they’d be more compassionate.

Several participants noted that the perception about people with mental illnesses as being violent, dangerous, and unpredictable also produces fear among the general public.

Another concern expressed by many participants was that, as a group, people with mental illnesses are viewed as homogeneous, without recognition of their diversity. Participants spoke about how the public incorrectly attributes a range of social problems (e.g., homelessness, violence, crime) to mental illness:

When anything goes wrong, like someone jumping from a bridge, the public thinks it’s a mental problem or mental illness. People think about the Downtown East Side [one of Canada’s most marginalized urban communities] or drugs and alcohol when they think about mental illness.

Indeed, the narratives indicated that public perceptions of people with mental illnesses – often shaped
by sensational news stories or street-level interactions with persons suffering from untreated mental illnesses – affected participants’ feelings about being associated with this group.

Social Identity/Location

Participants discussed their experiences of being separated from normal society and becoming a member of ‘the mentally ill.’ In one sense, social separation was described as a feeling of being different from other people, which was exacerbated by not being able to engage in normal activities on account of the effects of mental illness:

I can’t hold down a job . . . Made me feel like defective merchandise . . . Couldn’t do the stuff that normal people do. It ruined my marriage.

Social separation was also described as something that was self-imposed, such as choosing to withdraw from social situations in anticipation of negative social reactions:

I avoid talking to my neighbours because I’m worried that they’ll ask me ‘what do you do?’ and I’ll have to explain my mental illness and forensic involvement. [I] stopped going out to coffee as much because people will ask ‘what do you do?’ and I can’t tell them because of the stigma. I don’t want them to look at me differently. It’s better to be seen a stranger than mentally ill.

Additionally, participants spoke about social separation as something that was externally imposed, such as when they are socially excluded or rejected by family and friends:

When everyone thinks you are mentally ill, they’re not too quick to be friends.

The participants’ responses contained many references to the feeling that their identities had been engulfed by mental illness:

If I’m off my game, everyone thinks it’s my illness acting up. Just because I’m feeling down doesn’t mean that I’m going into a suicidal depression!

They [family members] say ‘take your pills’ when I do something wrong, like making a wrong turn when driving.

Related to this, one participant described the joy that he felt when his parents threw away a stack of books that they had collected about schizophrenia: They now identify with other aspects of my life that I enjoy, such as fishing and boating.

Participants’ narratives related to this theme revealed their continuous efforts to feel, and be seen by others, as ‘normal’ – a process that may require them to avoid social situations altogether.

Social Disadvantage

Participants shared their experiences with various forms of disadvantage that intersected with having mental illnesses. A predominant narrative within this theme was the way in which the symptoms of their mental illness and medication side effects prevented participants from participating in employment and educational activities, and building meaningful social relationships:

I got into UBC [University of British Columbia] years ago, but couldn’t go because of the voices.

The medications make me dizzy and drowsy, which makes it difficult to work.

I was getting sick a lot and friends were disappearing on me.

They doped me so much, I can’t have sex or enjoy sex.

Many participants referred to the restrictions that were imposed on them because of being poor, or not being able to find and retain adequate housing:

How can people with mental illness make important contributions to society on a limited income?

I always think that if I say the wrong thing, I’ll lose my housing.

They [prospective landlords] thought that I could make a problem for them, or they wanted to deal with someone without a mental illness.

Some of the responses suggested that the stigma related to other social and health conditions were greater than the stigma associated with mental illnesses: Most of the stigma is from not having social status – job, money, education – from poor life choices, not as a result of the illness.

Participants’ narratives of social disadvantage reflected their layered experiences of stigma, the complexity of the lived experiences of mental illnesses, and the ways in which the stigma of mental illnesses impacted upon their social well-being.

Passing-Managing-Overcoming

This theme relates to the ways in which participants coped with mental illness-related stigma. A common concern related to the disclosure of mental illnesses, particularly the angst associated with the possibility that their illness would be exposed:
How am I going to pull it off? Am I scaring somebody when I say that I’m schizophrenic? There are things that I don’t feel comfortable doing. It [stigma] exists when you talk about your illness.

I don’t tell people. I have in the past and they look at me like I’m in outer space. I tell them that I’m depressed and stressed out, not that I’m psychotic. If I said ‘schizophrenia’, they wouldn’t understand.

Several comments within this theme aligned with Goffman’s (1963) concept of ‘passing’; that is, trying to appear like someone who does not have a stigmatizing status or condition:

I adjust my behaviour and try not to show side effects [of medications]…. I dress up nicely so people don’t think I am mentally ill. Keep clean and keep shaven so people won’t suspect.

I try to emulate others, act normal… pretend not to hear voices.

Participants also shared their strategies for managing and overcoming stigma:

You have to weave yourself through people’s patterns of negativity. Just live your life and carry on.

Try and think positive. That is the main thing that I do.

Try to think happy thoughts.

Some participants noted that their relationships with family and friends had remained intact or, in some instances, had become stronger as a result of their struggles with mental illnesses and stigma:

My family loves me more.

My friends don’t care that I have a mental illness or that I get treatment.

Several participants focused on their strengths in order to overcome stigma, and drew strength from having to overcome the adversity resulting from mental illness-related stigma:

Stigma made me keep quiet about it [mental illness], but also made me more determined to get help.

Stigma motivated me to seek spiritual help . . . got me thinking that I want to be normal. Stigma positively affected my recovery by making me stronger.

I want to surpass the stigma… just takes time.

The narratives in this theme support the notion that despite multiple challenges in dealing with stigma, people with mental illnesses exhibit enormous strength and resilience, and are able not only to cope with stigma but also to overcome it.

Discussion

The qualitative analysis revealed how stigma was perceived and experienced by people with mental illnesses who received compulsory community treatment services. While compulsory treatment was thought to contribute to stigma, participants’ narratives suggested that it was not the predominant stigma-related problem. Rather, it was entangled with a myriad of other stigma-producing factors associated with the direct effects of mental illnesses (symptoms), social disadvantage (unemployment, poverty), and lifetime experiences with the mental health system. Underlying many of the narratives about stigma were feelings of powerlessness, devaluation, and oppression.

Overall, the study found that the perceptions and experiences of people who use compulsory community treatment services were not distinctly different from those which have been documented among other mental health populations (e.g., Camp, Finlay & Lyons, 2002; Bhui, Shanahan & Harding, 2006; Jensen, & Wadkins, 2007; Link, Castille & Stuber, 2008). Published results of quantitatively-measured levels of self-stigma reported by this sample also support this finding (Livingston et al., 2011). Similar to prior research in this area, the present study documented a complexity and diversity of opinions about the degree to which compulsory community treatment impacted experiences of stigma (Canvin et al., 2002; Gibbs et al., 2006; O’Reilly et al., 2006; Tan, Stewart, Fitzpatrick & Hope, 2010).

A unique contribution of the present study was the finding that compulsory community treatment may have prevented some people from achieving social advancement and attaining reputable social roles. Some participants spoke about how the conditions imposed on them through compulsory community treatment disrupted their lives and hampered their recovery. These barriers compounded those that are directly related to mental illnesses and other forms of marginalization (e.g., unemployment, poverty). Compulsory treatment also increased the likelihood that individuals with mental illnesses will be exposed to situations, such as police apprehensions and medication-driven treatment plans, which may be perceived to be unfair or stigmatizing. In line with other research in this area (Sibitz, Unger, Woppmann, Zidek & Amering, 2009; Corrigan et al., 2010), participants in the present study actively managed and resisted stigma.
Limitations

The present study's findings should be considered within the context of several methodological limitations. First, the interviews were not audio recorded to establish an environment of openness and trust with participants, many of whom were actively experiencing paranoia and delusional thinking as a result of their illnesses. Participants were also wary about information being disclosed to treatment staff who had power over their legal status. Because narratives were not recorded and transcribed verbatim, the richness and depth of the qualitative data may be limited. Second, the qualitative analysis was conducted by a single rater, which creates a potential threat to the validity and reliability of the results. A qualitative codebook, which contained code lists and descriptions, was developed to maximize reliability and transparency of the analytic process. Third, the results are based on the experiences of 91 people receiving compulsory community treatment services in BC, Canada – primarily from forensic mental health services in Metropolitan Vancouver. In light of this, the transferability of these findings to compulsory community treatment populations in other jurisdictions, especially those with different mental health service delivery models, should be made with caution.

Conclusion

Regardless of whether people with mental illnesses use treatment services on a voluntary or involuntary basis, this study suggests that they share a common struggle for choice, autonomy, respect, fairness, inclusion, and equality. For our participants, stigma was produced by various experiences that intersect with having mental illnesses and being socially disadvantaged. Mental health clinicians should be mindful of a small subgroup of participants who considered compulsory community treatment as being highly unfair and stigmatizing, as this may adversely affect treatment engagement and the effectiveness of clinical interventions.

References


