


Dealing With Discrimination in Physical Health Care Services: Strategies of People With Mental Health and Substance Use Conditions

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Abstract

Discrimination against people with mental health and substance use conditions (MHSUC) by health professionals contributes to the poor physical health outcomes this group experiences. We surveyed people with MHSUC in Aotearoa New Zealand to explore how they experienced and responded to discrimination from physical health services. Participants identified 6 strategies used to avoid or minimize the impact of discrimination. Avoidance strategies included not seeking help, not disclosing MHSUC diagnoses and changing or seeking out health professionals who did not behave in discriminatory ways. Minimizing strategies were being a “model patient,” taking a support person to consultations or advocating for what they needed, even in the face of discrimination. Physical health services must focus on providing non-discriminatory care to reduce the need for compensatory strategies and improve care of physical illness for people with MHSUC.

Keywords

discrimination, stigma, mental illness, qualitative research, patient perspectives/narratives

Introduction

Poor outcomes from physical health issues in people with mental health and substance use conditions (MHSUC) are well documented, include higher mortality and lower life expectancy,¹⁻⁴ and have persisted despite efforts to improve them.^{5,6} Physical conditions for which people with MHSUC have poor outcomes include cardiovascular disease, respiratory disease, diabetes, and cancer.⁷⁻⁹

The reasons for these poor outcomes are complex and multifactorial but can be partly attributed to lower quality physical health care^{10,11} including delayed diagnosis, lower rates of screening, and suboptimal treatment of physical conditions.^{7,12}

Discrimination (in this context, unfair treatment due to a person’s diagnosis of MHSUC) by health care professionals is a key factor contributing to the provision of lower quality care.^{13,14} This is manifest by people with MHSUC having physical symptoms misattributed to mental health;¹⁵⁻¹⁷ given less timely or effective treatment;^{13,15} and being deterred from seeking help because of past experiences of discrimination.^{13,18} Causes of discrimination include lack

of knowledge or familiarity with MHSUC, negative beliefs (stereotypes) about people with MHSUC and negative attitudes and emotions (prejudice) towards people with MHSUC.¹⁷⁻²¹

Much of the research into the physical healthcare of people with MHSUC has come from the perspective of the health system or health professionals rather than people with MHSUC.^{22,23} Previous qualitative research into discrimination from the perspective of people with lived experience of MHSUC has established that discrimination

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from health professionals can be readily identified^{24,25} and causes barriers to physical healthcare across all domains of care, from perceiving a need and seeking care, to accessing and participating in care and receiving appropriate assessment, treatment, and follow-up.^{13,18,22,26} Most of this research has explored experiences of discrimination and barriers or facilitators to care but has not specifically focused on identifying strategies that people use to deal with discrimination.^{22-25,27,28} Understanding how people with MHSUC respond to discrimination in healthcare can help providers and health systems to support responses that are positive and improve engagement and counteract responses that lead to disengaging with care.

This survey of adults with MHSUC in Aotearoa New Zealand was one component of a larger research project investigating the contribution of health services in exacerbating or mitigating unequal physical health outcomes in people with MHSUC. This project also involved analysis of routine datasets and in-depth interviews. The survey component of the research explored experiences of receiving physical healthcare, including participants' responses to discrimination from service providers.

Methods

An anonymous Qualtrics online survey was run from 31 January to 1 April 2022, aimed at adults (people 18 or older) who in the past 5 years had used health care services for MHSUC and engaged with any health care service for a physical health issue. Respondents were recruited via advertisements on social media by the researcher team and research advisory group, distribution through online newsletters and email lists from Government and non-governmental organizations and services, Māori health networks, and mental health providers. The survey explored experiences of physical health care, with a combination of closed and open-ended questions asking about experiences of 5 physical health settings (general practice, emergency departments, hospitals, pharmacies, and other health services), use of a support person, not seeking help for a physical health issue, and how physical health care could be improved. Quantitative results on experiences of discrimination in primary care have been published elsewhere, which includes more details about the development and dissemination of the survey.²⁹

The primary qualitative analysis of responses to open-ended questions focused on exploring how people with MHSUC experienced discrimination and their perceptions and understanding of why the discrimination occurred. These results will be published separately.³⁰ For this secondary analysis, 2 phases of coding were completed of participants' responses to open-ended questions. The first phase involved structural coding,³¹ where participants' survey responses were grouped using an existing stigma framework that defined public and self-stigma into components of stereotype, prejudice, and discrimination.³² During this

coding, it was noted that as well as describing discrimination from health providers, survey respondents also reported on ways they themselves responded to discrimination. A second phase of coding was then completed, involving descriptive coding to identify how participants acted and changed their behavior when they perceived or felt at risk of discrimination.³³ This second phase of coding, that described strategies that people with MHSUC used in response to discrimination in physical healthcare, is reported here.

The data analyst (FI) undertook the first phase of coding, reviewed by qualitative researcher and lived experience contributor (DP). The second phase of coding by FI was independently reviewed by DP and RC (project lead) and final results were appraised by subject matter experts and researchers (SEP, TH, MC), with interpretation provided by the whole team.

Verbatim quotes are used to demonstrate themes evident from the second phase of coding, identified by age bracket and gender (F = female, M = male, GD = gender diverse, including non-binary and transgender).

Results

The final survey sample included 354 eligible individuals of whom 253 answered at least 1 open-ended question. Participants included people with a range of MHSUC, often more than 1. Further details on participants are in Table 1. Participants described a variety of strategies whereby they either avoided or minimized the impact of discrimination from physical health services.

Avoidance of Discrimination

Three approaches focused on avoidance. The most definitive and commonly mentioned strategy was to **not seek help**, usually due to the person's fear they would be ignored, disbelieved, or be told that their physical symptoms were caused by the MHSUC diagnosis:

I generally don't seek help or I wait until something is really serious because I'm worried [healthcare providers] think I'm making it up or that it's to do with my mental health. (18-25, F)

Although participants were aware that not seeking help could have detrimental consequences, they also weighed up the negative impact of discrimination on their mental well-being:

I've put off seeing the doctor . . . because I've been afraid of it adding more stress or being treated like a child. (18-25, F)

The choice to not seek help could be a direct consequence of previous experiences of discrimination:

Table 1. Characteristics of Participants.

Characteristic	n (%) for total survey sample	n (%) for those who responded to open-ended questions
Age		
18-25 years old	57 (16%)	43 (17%)
26-35 years old	91 (26%)	65 (26%)
36-45 years old	65 (18%)	49 (19%)
46-54 years old	51 (14%)	42 (17%)
55 + years old	42 (12%)	37 (15%)
Missing	48 (14%)	19 (8%)
Gender		
Female	228 (64%)	172 (68%)
Gender diverse (non-binary and transgender)	15 (4%)	13 (5%)
Male	59 (17%)	44 (17%)
Prefer not to answer/missing	52 (15%)	24 (10%)
Ethnicity		
Māori	58 (16%)	47 (19%)
Non-Māori	51 (14%)	21 (8%)
Missing	245 (69%)	185 (73%)
Sexual orientation		
Heterosexual	197 (56%)	149 (59%)
LGBQA+	107 (30%)	83 (33%)
Missing	50 (14%)	21 (8%)
Diagnosis^a		
Addiction	58 (16%)	44 (17%)
Anxiety	225 (64%)	168 (66%)
Bipolar disorder or schizophrenia	59 (17%)	50 (20%)
Depression	241 (68%)	181 (77%)
Personality disorder	41 (12%)	35 (14%)
Post-traumatic stress disorder	54 (15%)	42 (17%)
Number of diagnoses		
1	43 (12%)	36 (14%)
2	114 (32%)	85 (34%)
3	79 (22%)	58 (23%)
4+	53 (14%)	44 (17%)
Missing	65 (18%)	30 (12%)
Total	354	253

^aThis percentage is for all those who reported a diagnosis in the whole sample; the proportions are higher if people who did not report any diagnosis are excluded from the denominator.

As soon as they see my diagnosis of borderline personality disorder and history of addiction they would treat me as if I was problematic and an attention seeker, which... has always stopped me from going to ED (26-35, F)

Not seeking help could also occur in anticipation of discrimination:

When I took a small-medium overdose I didn't go to the hospital because I was too scared of the nurses judging me. (26-35, F)

Another avoidance approach was to **not disclose** MHSUC diagnoses to health professionals whenever possible:

I left the South Island and started over because health care professionals see the mental illness first and make assumptions rather than listening to my symptoms. (46-54, F)

Non-disclosure was used in order to be “treated *normally* (26-35,M).” This often meant that people’s physical symptoms were appropriately addressed, without the MHSUC diagnosis distracting from the physical concerns:

Once I moved and failed to disclose my mental illness, my physical condition was taken seriously and dealt with. (36-45, M)

The downside of this approach was that people could miss out on mental health support or integrated care.

The third avoidance approach was to **change to or seek out a non-discriminatory health professional**:

I've purposely sought out a GP who is understanding of mental health so I have had only good experiences. (18-25, GD)

Supportive clinicians were found through recommendations from others or by trial and error:

I changed to my current GP service because of their exceptional care, they are accommodating, listen rather than speak over you and work with you to find the best solution. (26-35, F)

Some people commuted long distances to reach preferred and trusted providers, valuing non-discriminatory care over the inconvenience of travel:

I chose to stay with my current GP even though the location is inconvenient because they are very supportive and understanding of my health issues. (36-45,F)

Changing providers was not always possible for people who had limited options and fear of being judged or labeled could prevent change:

I've wanted to change practitioners, but I've generally just stuck it out... to avoid any appearance of being 'non-compliant' or 'doctor shopping'. (26-35,GD)

Minimising the Impact of Discrimination

People with MHSUC also employed strategies to minimize the impact of discrimination. This could involve deliberately presenting as a “**model patient** (26-35, GD)” who is compliant and non-complaining, even if that meant not confronting poor practice or not asking for clarification or help:

I avoid raising mental health issues with the diabetes clinic ... I feel like it would have been detrimental to talk to them about my anxiety and how hard that makes it for me sometimes to manage my blood sugar. (36-45,M)

Presenting as articulate and a good communicator were ways to increase the chance of being taken seriously: "I have a good bedside manner, communicate well so don't have any issue (46-54, F)." Conversely, showing emotion was seen to undermine credibility, making it more likely that health professionals would discount the possibility of "genuine" physical issues: "as soon as I get upset and cry I lose credibility as being physically unwell (46-54, F)."

Taking a **support person** to health consultations was another strategy people used to improve the interaction with health professionals and decrease the probability of discrimination:

I always take support to doctor's appointments (other than my GP) as I have no trust in new doctors and have been burnt so many times ... if I take a witness it is harder for them to blame stuff on mental health. (18-25,F)

However, not everyone wanted to take this approach, if it meant they would be perceived as less competent: "I am capable of attending my own appointments regarding my physical health (46-54,F)." Some people were not aware that support was an option: "[this was] never offered or presented to me as an option (26-35, GD)" or found it difficult to access: "I often cancel appointments because support is not available (55+, F)." Others thought it should be offered more systematically: "They need peer support in every ED (55+, F)."

A few people described the approach of **advocating for what they need** as a way of confronting discriminatory care:

It's only within the past year I've really fought for my own physical health no matter how I get treated because I'm worth fighting for. (26-35,F)

This required confidence, persistence and conviction:

I have since resumed ... treatment with a different gynaecologist but it's only because I feel more able to handle the care, not because the care has improved. (26-35,F)

However, not everyone could sustain this kind of approach:

I gave up advocating for myself even when I am experiencing many physical symptoms because of how I was treated and in fear of being told it's all in my head. (18-25,F)

Making a complaint about unsatisfactory care was a specific strategy that some people used to fight for what they needed, although not everyone felt able to do this: "[the physio] told

me to make a complaint – I never did as I already felt unheard (46-54,F)."

Discussion

This study found that people with MHSUC use a variety of strategies to avoid or minimize the impact of discrimination from physical health services (Table 2). Although some strategies may improve experiences of physical healthcare, others could lead to harm, particularly when healthcare is not sought for a serious issue, or unsafe practices are not called out by patients who fear further discrimination by being judged as "difficult." Other strategies represent an additional burden for people with MHSUC in terms of extra time, cost, resource, or cognitive load, such as taking a support person or self-advocacy.

Table 2. Summary of Strategies Used by People With Mental Health and Substance Use Conditions in Dealing With Discrimination From Physical Healthcare Services.

Avoidance strategies: used to circumvent experiences of discrimination

Don't seek help	The ultimate response to discrimination that has previously been experienced or is expected to occur by shunning services unless symptoms are unendurable or life-threatening
Don't disclose a mental health or substance use diagnosis	A strategy used when interacting with new or unknown health providers, at least until trust and rapport is established
Change to or seek out a non-discriminatory health provider	A pro-active response to discrimination but one which requires knowledge of and access to non-discriminatory health providers

Minimizing strategies: used when discrimination may not be avoidable

Be a model patient	Presenting oneself as competent, coherent, compliant, and calm is done to ward off judgments and stigmatizing attitudes from health providers
Take a support person	A support person, whether a friend, family member, peer or mental health or addition professional, is taken to physical healthcare appointments to be a witness, advocate and arbiter of fair treatment
Advocate for what you need	Being strong and perseverant in the face of discrimination in order to get the attention and treatment that is warranted, including making a complaint

Our findings align with prior research which found many people with MHSUC have experiences of being treated as incompetent and having their agency undermined²² which contributes to a protective strategy of non-disclosure.²⁰ Other studies confirmed the burden of discriminatory experiences such as being dismissed, not being believed or listened to, which made standing up for oneself difficult, especially if the person with MHSUC had been exposed to so much discrimination that it became normalised.^{18,32} Therefore, while empowerment of people with MHSUC to identify discrimination and seek or advocate for better care may be useful, health care providers have an ethical and professional duty to provide non-discriminatory care, to improve physical health outcomes of people with MHSUC.

Prior research on interventions to reduce mental health stigma has been limited by a focus on short-term outcomes and the impact of knowledge and attitudes rather than behavior change.^{34,35} There is suggestion that the most promising interventions for providers may involve contact with individuals that clearly contradict common stereotypes about MHSUC.^{13,36} Providers that are not specialists in psychiatry or addiction also need adequate training and support to manage MHSUC with confidence and competence.^{14,20} In addition, health systems and structures need to prioritize improving the physical healthcare of people with MHSUC, with systemic changes potentially acting to reduce experiences of discrimination. For example, effective integrated care, where mental and physical healthcare services work closely and collaboratively in providing care for people with MHSUC,³⁷ could reduce the need for people to use discrimination avoidance strategies. Reducing the time constraints on physical health services could also allow both physical and mental health concerns to be adequately addressed in a single consultation,^{20,38} reducing the need for people with MHSUC to use discrimination minimizing strategies.

This was a relatively small survey, with a self-selected sample not necessarily representative of all people with MHSUC in Aotearoa New Zealand. However, similar findings have been reported in other qualitative research exploring experiences of people with MHSUC seeking physical health care which identified “survival strategies” employed by patients to improve their chances of receiving appropriate care.²² These survival strategies included preparing for a consultation by looking up symptoms and being more assertive, asking questions, seeking specific help or referrals, choosing a more suitable provider and not talking about MHSUC.²² Non-disclosure of MHSUC was also identified in other research^{17,20} as well as having an “advocate with clout” who could facilitate medical appointment access and attend in support.²³ The strategy of not seeking help because of past or expected discrimination in people with MHSUC has been well documented.^{13,18}

More research is needed into the relationship between discrimination and physical health outcomes in people with MHSUC, particularly into factors that mediate and can

interrupt this relationship. From the quantitative results of this survey, discrimination and diagnostic overshadowing was experienced always or most of the time in 10% and 20% respectively of people with MHSUC attending primary healthcare,²⁹ indicating that these are serious issues for a significant minority of people, not counting those who choose not to seek healthcare. Future research to quantify the amount of discrimination experienced by people with MHSUC in different settings and the frequency and impact of strategies used in response to discrimination would help in the development of quality improvement interventions for health services and supportive interventions for people with MHSUC.

Conclusion

People with MHSUC employ a variety of strategies to avoid or minimize the impact of discrimination from physical health care providers. Some of these may impact quality of care (eg, choosing not to seek help or not disclosing MHSUC) or impose an additional burden on the patient (eg, having to find an appropriate provider, take a support person or advocate for physical healthcare). Health services that provide equitable, non-discriminatory care will reduce the requirement for people with MHSUC to engage these types of strategies and therefore have the potential to improve physical health outcomes in this population. Ways to achieve this include ongoing education and training of health providers and commitment to system changes to reduce discrimination.

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Declaration of Conflicting Interests

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Ethical Approval

This study was approved by the Southern Health and Disability Ethics Committee (reference: 21/STH/216).

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Statement of Informed Consent

Participants were provided with information about the study, including privacy, confidentiality, and use of the information provided, at the invitation to the survey and before the survey began. Informed consent for use of their anonymized information to be published in this article was inferred by their engagement with the online survey.

Statement of Human and Animal Rights

All activities in this study were conducted in accordance with Southern Health and Disability Ethics Committee approved protocols.

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