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Qualitative analysis of mental health service users' reported experiences of discrimination

Hamilton S, Pinfold V, Cotney J, Couperthwaite L, Matthews J, Barret K, Warren S, Corker E, Rose D, Thornicroft G, Henderson C.
Qualitative analysis of mental health service users' reported experiences of discrimination.

Objective: To better understand mental health service users' experiences of stigma and discrimination in different settings.

Method: An annual telephone survey of people with a mental health diagnosis conducted to evaluate the Time to Change antistigma campaign in England. Of 985 people who participated in 2013, 84 took part in a qualitative interview which was audio recorded. Of these, 50 interviews were transcribed and thematically analysed to explore accounts of discrimination. We analysed common types of behaviour; motivations ascribed to the discriminators; expectations of what fair treatment would have been; and the impact of discrimination on participants.

Results: Discrimination was most common in five contexts: welfare benefits, mental health care, physical health care, family and friends. Participants often found it hard to assess whether a behaviour was discriminatory or not. Lack of support, whether by public services or by friends and family, was often experienced as discrimination, reflecting an expectation that positive behaviours and reasonable adjustments should be offered in response to mental health needs.

Conclusion: The impact of discrimination across different settings was often perceived by participants as aggravating their mental health, and there is thus a need to treat discrimination as a health issue, not just a social justice issue.

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Key words: mental health; social stigma; surveys and questionnaires

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Significant outcomes

- Assessing a behaviour as discrimination is shown to be difficult for people, and this has implications for those trying to measure the incidence or impact of discrimination.
- Participants told us that the discrimination they did face often impacted negatively on their mental health. There is thus a need to treat discrimination as a health issue, not just a social justice issue.
- The strategies for addressing behaviour described as stigma and discrimination by service users require tailoring for specific settings and contexts.

Limitations

- The qualitative interviews were by telephone, which can limit rapport and building of empathy important for data quality.
- The study used a random sample of people under the care of specialist mental health services in England, but the response rate was low despite extensive strategies to address this short coming.
- This qualitative study has few non-White British participants and women made up two-thirds of the sample. Repeating this research with well-defined population groups is recommended.

Introduction

Before antistigma programmes such as Time to Change (1) can successfully tackle discrimination, those delivering them need to understand the range of discriminatory behaviours that people with mental health problems experience, from whom and how, alongside its impact. Qualitative studies can provide valuable insights for understanding, measuring and challenging mental health-related discrimination. Despite this, it is a relatively neglected area of research. In 2004, a review (2) found only 17 of 123 studies of mental health stigma used qualitative methods. The term 'stigma' has often been used broadly to refer to the devaluing of particular social identities or characteristics, including labelling, stereotyping, loss of status and discrimination (3). Studies of stigma tend to examine negative attitudes and beliefs about people with a mental health diagnosis. Only four studies found by the review considered the enacted component of stigma – discrimination – and none gathered data directly from people with mental health diagnoses, instead speaking to family members, doctors and the general public. Since 2005, qualitative approaches have become somewhat more common, with a PubMed search finding a further 22 studies published. The lack of attention given to qualitative approaches leaves important questions that still need to be answered, particularly around the experience and impact of discrimination from those who have been the subject of it. Qualitative research can also be used to further refine our understanding of what discrimination is and how it can be addressed.

Previous qualitative studies have often identified the same groups and settings as the most common sources of discrimination: family members, health-care professionals and employers (4–6). A small number of studies have looked at specific settings – for example hospitals (7–9) – or circumstances – for example parenting (10). The range of behaviour types identified is also fairly consistent across the literature, including the expression of prejudicial views (such as dangerousness), overprotection, having views discounted or disbelieved, being avoided, structural discrimination and experiencing physical abuse or neglect (5, 11–13). We have found no previous studies that compare accounts of discrimination describing different types of behaviour or different sources or settings. This study was conducted to address this gap, to further understand the common features of discrimination as experienced by people with mental health problems.

To quantify discrimination across a wider range of life areas, we developed the DISC (14). This has been used to assess experiences and anticipation of

discrimination globally amongst people with schizophrenia (15) and depression (16) and to evaluate the Time to Change antistigma programme against their target of reducing discrimination by 5% (17). At the same time, its development and use have highlighted the difficulties people experience in assessing whether or not a behaviour is discriminatory (13). The DISC is valuable for assessing the occurrence, nature and severity of discrimination. Qualitative research is needed, however, to explore the way in which participants identify and experience negative behaviours.

Aims of the study

Our study specifically set out to explore individual accounts of mental health discrimination, across 22 different settings, in order to better understand how negative behaviours were experienced in order for interventions to be better designed and appropriately targeted.

Method

We undertook a collaborative piece of research with people who have a dual identity as someone with lived experience of mental health problems and a person employed as a researcher. This strategy of collaborative research, fusing academic research expertise and lived experience research expertise is an explicit design feature of this study. It was intended to provide a perspective on the data which reflected the practical and emotional impact of living with a mental health diagnosis and experiencing discrimination. Researchers on the study explicitly used these experiences when interviewing and analysing the data, taking a reflexive stance throughout to consider how this affected their interpretation of the accounts given. Further information about this approach as used in the Viewpoint study is published elsewhere (14).

Participants and data collection

Participants were a subsample of respondents to the 2013 Viewpoint survey, an annual survey used to evaluate the impact of Time to Change using the DISC-12 interview (see Corker et al, pages 6–13 in this issue) (15). The DISC-12 asks participants whether they have been treated unfairly, within the last year, in a range of contexts, including, for example, by family, by friends, in finding a job or in healthcare settings. People with a mental health diagnosis were randomly sampled across five mental health trusts in England. A total of 9599 were invited to take part and 985 participated

in telephone interviews (16). The interviews were assigned to one of a team of 22 trained interviewers, over 85% of whom had personal experience of mental health problems, based on matching availability of participant and interviewer. Full details of the methodology for the overall study are reported elsewhere (18, 19).

Four of the Viewpoint interviewers with personal experience of mental health problems expressed an interest in being involved in the sub-study, and they received additional training in qualitative interviewing. They sought consent from participants to audio record all the interviews randomly assigned to them over a period of 2 months within the larger Viewpoint study. Only, the interviews conducted by these four service user interviewers were recorded. We set a target of 50 interviews for analysis. A total of 84 interviews were recorded, and these participants were probed for additional details of the discrimination they experienced. Interviewers used their own judgment when probing, but were particularly encouraged to ask follow-up questions to capture detail on who was involved, the context of the incident, the discriminatory behaviour and any impact on the participant, including emotional impact. Of these, the 50 interviews with the most accounts of discrimination experiences – those who gave examples of discrimination in the highest number of life areas, as defined by the DISC-12 – were selected for full transcription and analysis. Characteristics of the participants are shown in Table 1.

Analysis

Thematic analysis included a within-case and across-case approach (18) to ensure that the process of coding did not lose the context of the data. We used a two-stage process to identify key patterns across and then within individuals' accounts. First, the four Viewpoint interviewers with personal experience of mental health problems and two other researchers (SH and JC) familiarised themselves with the data. Drawing on previous literature, they jointly constructed a coding framework of nine themes (see Table 2). All data were coded using these themes by the six researchers and reviewed by one researcher to ensure consistency.

Next, we identified the five life areas (out of 22 in the DISC) in which discrimination was most reported within this sample: welfare benefits, mental health care, physical health care, family and making/keeping friends. We identified the three most common discrimination types for each life area to create pairings for which multiple accounts could be analysed (shown in Table 3).

Table 1. Participant characteristics, participants included in the qualitative study compared to overall survey sample

| Characteristic | Qualitative sample 2013 (n = 50) | Complete sample 2013 (n = 985) |
|--------------------------------------|-------------------------------------|-----------------------------------|
| Gender n (%) | | |
| Male | 17 (34%) | 365 (37.1%) |
| Female | 32 (64%) | 616 (62.5%) |
| Transgender | 1 (2%) | 4 (0.4%) |
| Age (years) | | |
| Range | 25–64 | 18–65 |
| Mean | 44 | 44 |
| Ethnicity n (%) | | |
| White British | 44 (88%) | 844 (86%) |
| Other White | 1 (2%) | 42 (4%) |
| Black or Mixed Black and White | 3 (6%) | 58 (6%) |
| Asian or Mixed Asian and White | 1 (2%) | 32 (3%) |
| Other Mixed | 0 (0%) | 5 (0.5%) |
| Other | 0 (0%) | 2 (0.2%) |
| Did not wish to disclose | 1 (2%) | 2 (0.2%) |
| Employment status n (%) | | |
| Unemployed | 33 (66%) | 582 (59%) |
| Part-time employed | 5 (10%) | 91 (9%) |
| Full-time employed | 3 (6%) | 90 (9%) |
| Self-employed | 2 (4%) | 26 (3%) |
| Retired | 3 (6%) | 75 (8%) |
| Volunteering | 3 (6%) | 62 (6%) |
| Training/education | 0 (0%) | 48 (5%) |
| Other | 1 (2%) | 11 (1%) |
| Did not wish to disclose | N/A | N/A |
| Main diagnosis n (%) | | |
| Depression | 17 (34%) | 265 (27%) |
| Bipolar disorder | 6 (12%) | 181 (18%) |
| Schizophrenia | 2 (4%) | 137 (14%) |
| Anxiety disorder | 7 (14%) | 130 (13%) |
| Personality Disorder | 5 (10%) | 98 (10%) |
| Schizoaffective disorder | 1 (2%) | 21 (2%) |
| Eating disorder | 1 (2%) | 13 (1%) |
| Multiple diagnoses | 3 (6%) | 34 (4%) |
| Substance misuse/addictions | 0 (0%) | 1 (.1%) |
| Other | 4 (8%) | 40 (4%) |
| Missing | 4 (8%) | 59 (6%) |
| Received involuntary treatment % (n) | | |
| Yes | 13 (26%) | 343 (35%) |
| No | 37 (74%) | 639 (65%) |

Each account was analysed separately by two researchers to explore patterns within the accounts. For each account, a table was created to produce an overview, including: i) the context/behaviour; ii) participants' rationale for the behaviour; iii) participants' expectations of non-discriminatory behaviour in this context; and iv) the impact of the behaviour. The patterns identified are presented in the following section and reflect commonalities across the accounts. Quotations are used to illustrate the findings.

Results

Welfare benefits

There was overlap between the three most common types of discrimination reported in relation to

Table 2. Coding framework

| | | |
|-----|---|--|
| 1 | Mistreatment | Behaviours <i>intended</i> to cause emotional and/or physical harm. |
| 1.1 | Verbal abuse | Verbal (including written) behaviours intended to cause emotional pain. |
| 1.2 | Physical abuse | Physical behaviours intended to cause emotional and/or physical pain (e.g. violent behaviour towards person or property). |
| 1.3 | Tormenting | Behaviours intended to cause emotional pain that do not involve explicit physical or verbal abuse, for example intimidation or repeated annoyance. |
| 1.4 | Taking advantage | Behaviours that lead to the participant being taken advantage of (e.g. theft, exploitation or being put into a weak position in decision-making). |
| 1.5 | Impact | Description of impact on a participant's life. |
| 2 | Social distance | |
| 2.1 | Social distance by others | (e.g. avoidance or not being invited to social occasions). |
| 2.2 | Social distance by self | Participants' own behaviour leading to social distance (e.g. reluctance to meet with others or to go out). |
| 2.3 | Impact | Description of impact on a participant's life. |
| 3 | Stereotyping | Explicit or implicit judgements based on their diagnosis. |
| 3.1 | Judging competence | Explicit assumptions about what a participant is able to <i>do</i> (e.g. role as a parent, role at work). Includes patronising behaviour and talk. |
| 3.2 | Judging character | Assumptions about a participant's character or personality (e.g. weak, unstable, oversensitive, disorganised, aggressive). |
| 3.3 | Judging credibility | Judgements of a participant's credibility (e.g. GP attributing physical health complaints to a mental health condition). |
| 3.4 | Impact | Description of impact on a participant's life. |
| 4 | Organisational decisions | Decisions within organisations that reduce or withhold access to organisational services or where organisational decisions are applied inequitably. |
| 4.1 | System based | Decisions that are based on the systems, processes and policies of an organisation (e.g. being penalised by insurance companies). |
| 4.2 | Individual based | Inequitable decisions made by individuals as part of an organisation (e.g. employers, health professionals, welfare staff) |
| 4.3 | Impact | Description of impact on a participant's life. |
| 5 | Lack of understanding or support | |
| 5.1 | Lack of support | Participant not receiving the practical or emotional support they expect from others |
| 5.2 | Not taking MH problems into account | Others do not take mental health problems into account or fail to make appropriate adjustments |
| 5.3 | Lack of understanding/empathy | Participants' impression that others do not understand their experiences or show any empathy. |
| 5.4 | Not being heard | Views being ignored (distinct from assumptions about credibility). |
| 5.5 | Intrusive questioning | Inappropriate questions or breach of privacy. |
| 5.6 | Impact | Description of impact on a participant's life. |
| 6 | Overprotectiveness | 'Well-meaning' behaviour that gets it wrong from the perspective of the participant. |
| 6.1 | Overprotectiveness | For example, checking up on participants too often, not asking them to do ordinary things or being too wary about what may happen in the future. |
| 6.2 | Impact | Description of impact on a participant's life. |
| 7 | Dismissiveness | |
| 7.1 | Dismissiveness of mental health | Lack of belief in the mental health condition (e.g. treating the illness dismissively, or doubting severity of impact) |
| 7.2 | Silencing of mental health | People refusing to engage with the topic of mental health (e.g. nothing is spoken about in an adult way). |
| 7.3 | Impact | Description of impact on a participant's life. |
| 8 | The role of self | |
| 8.1 | Anticipated stigma (past experiences as triggers) | Participants changing own behaviour to avoid expected discrimination (e.g. not revealing diagnosis to others because they think they will be avoided or judged). |
| 8.2 | Self-stigma | Participants' expressions of feeling responsible when they have been treated in a way that reflects mental health discrimination. |
| 8.3 | Impact | Description of impact on a participant's life. |
| 9 | Positive experiences | |
| 9.1 | Positive experiences | Positive experiences resulting from a participant's mental health condition (e.g. receiving care or support not available to others) |
| 9.2 | Impact | Description of impact on a participant's life. |

welfare benefits received from the state: system based, dismissiveness and lack of understanding (themes are defined in Table 2). The majority of instances related to 'Work Capability Assessments' – the process in England through which entitlement to state benefits for people unable to work due to illness or disability is currently assessed – or other reductions in benefits.

Participants assessed these as discriminatory based on three judgements. First, that the

assessment disadvantages people with mental health problems over those with physical disabilities:

The form purports to address mental health issues, but when you're filling the form in, you feel invisible. [. . .] The whole way that it's drafted is just: can you stand up? Can you sit down? (Female, 52)

Linked to this relative disadvantage is the view that the system and those working within it do not

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Table 3. Top three discrimination types by setting

| Life area (total number of coded accounts) | Discrimination type (number of coded extracts) |
|--|--|
| Friends (48) | Social distance by self (6) Social distance by others (24) Lack of understanding (5) |
| Benefits (40) | System based (15) Lack of understanding (6) Dismissiveness (6) |
| Mental health (41) | Lack of support (12) Overprotectiveness (4) System based (5) |
| Physical health (33) | Judging credibility (7) Not being heard (5) Lack of support (7) |
| Family (53) | Social distance by others (10) Lack of understanding (15) Lack of support (8) |

have adequate expertise or understanding of mental health. Second, that the rhetoric of the UK government, as expressed through welfare policy, discriminates against people claiming welfare in general, and people with mental health problems in particular, by treating claims with suspicion and promoting a view of claimants as ‘scroungers’ (male, 64). This was seen within public discourse and in the behaviours of individuals within the benefits system which were described as ‘bullying’ (female, 52) and displaying a ‘presumption of guilt’ (male, 55) towards the claimant.

Third, participants reported that mental health-related needs and vulnerabilities are not taken into account when making decisions related to welfare benefits:

I felt as though the support period of me getting back into work was taken away without any sensitivity or awareness that it might upset my mental health and therefore we would be back to square one. (male, 49)

This reflects an expectation of ‘reasonable adjustments’ to ensure that the welfare system did not impact detrimentally on people with mental health problems compared to other people.

Participants described the detrimental effect of these experiences on their mental health resulting from negotiating the welfare system, living in financial hardship, and undergoing appeals and tribunal hearings. In one case, the participant described feeling ‘suicidal’ (male, 52) as a result of these stressors.

Mental health professionals

Participants’ accounts similarly described a lack of support from the mental health system and individuals within it. Participants gave examples of

being unable to access appropriate and timely treatment, including lack of out-of-hours services, inappropriate discharge from specialist services and long waiting times to access therapy. Participants often qualified this by acknowledging the financial pressures on services, reflecting a distinction between system-based discrimination and interpersonal stigma:

Mental health teams are very overstretched, they’re underfunded. There’s a lack of services that are available. They’re always closing. [...] it’s starting to affect people that need these critical services. (male, 46)

Others, however, gave examples of unsupportive individuals within mental health services, who failed to take account of personal circumstances and needs, particularly when the participant was in distress:

So he’d seemed quite prepared to abandon me in a state of crisis. And I was trying to tell him that I needed help. (female, 46)

The impact of these experiences included delayed access to treatment, prolonged distress and poorer relationships with professionals. As with the welfare benefits system, the mental health system was seen as a support structure, and expectations were of supportive, expert treatment. Some participants recognised the difficulty of differentiating between discrimination and failure to meet expectations:

I think sometimes you have your expectation of what you’re going to get and they don’t meet that expectation, so it feels like you’ve been treated unfairly. (female, 36)

In contrast, ‘overprotectiveness’ was a distinct form of discriminatory behaviour in which mental health professionals sought to make decisions on behalf of the individual. This went beyond providing support and advice in decision-making, leading to feelings of intrusiveness:

I have been discouraged from just going ahead [starting a family]. I’ve been told I have to discuss it with doctors first. [...] I feel it’s my private business, however, I would like their advice. (female, 36)

Physical health professionals

The ‘lack of support’ theme was also found in physical health services, although the focus was on individual behaviours, rather than system-based discrimination or lack of resources. Participants described rudeness or dismissiveness towards them which were attributed to professionals’ failure to take into account the needs and challenges faced

by individuals because of their mental health problems:

I missed some appointments because of [effects of medication]. They kicked me off the register. [...] I feel safer when I go there, because I see one doctor and he's right nice and very caring. But now they've kicked me off the register, I've just got nowhere else to go. (female, 52)

A second form of behaviour, specific to physical health care, was identified under the theme of 'judging credibility'. There were several accounts of practitioners not listening to them or not believing that participants had genuine physical health problems, instead attributing symptoms to the mental health diagnosis (a phenomenon often termed 'diagnostic overshadowing'):

I wish sometimes they'd just actually listen to what I'm saying, and they could see that it's not always a mental health problem. (female, 38)

This form of discrimination could have very serious consequences, with physical treatment being neglected or delayed:

I've stopped going to my GP. I keep having blackouts, I can't breathe sometimes [...] I think what's the point? Because they look at you and say, 'oh it's down to panic attacks', when you personally know that it isn't. (female, 38)

Participants generally had no difficulty attributing these behaviours to discrimination resulting from their mental health diagnosis. Unlike with mental health, participants generally had a clear sense of what they should be able to expect from physical health services and attributed the shortfall to their mental health diagnosis.

Family

Lack of understanding was a common theme in relation to family and overlapped with being dismissive of mental health problems, including being told to 'pull your socks up' (female, 62), that it is a 'choice' to be unwell (female, 28) or that the illness is not 'real' (female, 52). Some felt that this reflected a lack of caring on the part of family members who did not want to make the effort to understand – 'he isn't interested in understanding' (male, 51) – while others felt that it was in spite of best intentions – 'it's very difficult for families to understand' (male, 46).

Participants felt that they did not get the emotional or practical support they needed from family. Some attributed this to families having their own problems and struggling to provide them with

support as well; others described an unwillingness to openly acknowledge the mental health problem:

Because of their generation really, they couldn't give me any support because they wouldn't talk about it in front of their friends. (female, 36)

The other common behaviour from families was 'social distance'. This was often temporary, with family members distancing themselves when the participant was most unwell. In other cases, family members became completely estranged:

My daughter just left. [...] She left about four months back and I don't even know where she lives now. [...] she was saying she couldn't cope with my illness and things like that. (male, 64)

The sense that family 'couldn't cope' was common in the examples given:

My relationship with my family has been very much shaped by my mental illness. [...] sometimes they find it difficult, they won't speak to me [...] not in a malicious way, but because they just can't cope with what's happening to me. (female, 52)

The impact of social distancing was mostly negative; participants described feeling 'let down' (male, 54) and 'upset' (male, 56). One participant, however, described reduced contact with family as 'liberating':

It's gradually become quite liberating really, in the sense that my illness stems from my family environment. So in a lot of ways it was actually the turning point in getting back into work, being able to manage my condition. [...] I've not had an episode since I've had no contact with my family. (male, 49)

Friends

Lack of understanding and social distance by others were common discrimination types for friends as well as family, although social distance was the most common type described by far. Social distancing was more varied and sometimes harder to discern amongst friends than family. Friends were described as 'shying away' (male, 50) and 'turning their backs' (female, 62) or had stopped actively pursuing opportunities to socialise with them. There were two cases in which friends had explicitly cut off all contact.

As with family, participants attributed social distancing by friends to an inability to cope with their mental illness. Some participants reported feeling that others found being friends with them difficult because of their mental illness:

[They're] not really quite sure of how I'm going to behave [...] whether that will manifest itself, I guess, in a situation either in physical terms, whether I'll become distressed or disturbed some way. (female, 53)

Social distancing removed an expected source of support for many people.

I was quite disappointed that people who I trusted and thought were kind of close friends seem to have kind of gradually disappeared and not been very supportive. (-male, 49)

In addition to feeling isolated by others, participants described deliberately isolating themselves for various reasons, including feeling unable to cope with other people's reactions to the mental illness, loss of self-confidence or feeling like a burden. Social distancing by self and others were closely linked, and it was sometimes hard for participants to identify whether it was the result of others' behaviour or their own:

I know some of it's my fault [...] I haven't felt that I could go and ask. Everyone's got their lives but nobody comes knocking on my door to visit. (female, 47)

Discussion

This is the first study to explore in detail accounts of discrimination across a variety of settings and different types of behaviour. This has allowed us to compare accounts across professional or institutional settings and social settings. Our findings show that there is no simple assessment or criteria for ascertaining whether a behaviour will be experienced as discrimination. Such behaviours include *both* treating someone differently because of their mental health diagnosis *and* not treating them differently in a way that is considered to adequately accommodate the mental illness (as in the benefits system); *both* individuals behaving disrespectfully *and* failure to provide a service that is considered to be good enough at an organisational level (as in the mental health system); *both* failure to take the mental illness seriously *and* underestimating the individual's abilities or overestimating their weaknesses (as in health and family settings); *both* deliberate cruelty *and* an understandable difficulty for those without experience of a mental health problem to understand or cope with it (as in social settings). Discrimination is thus shown to be fraught with contradictions and subtleties that make accurate definition or measurement extremely difficult.

Our findings are broadly consistent with the previous literature in this field, particularly in the most common sources and the most common

behaviour types identified by participants. This study adds to an understanding of discrimination in several ways. First, it highlights that lack of an expected level of support or understanding, whether by public services or social networks, is frequently experienced as discrimination. This is important as it requires a definition of discrimination that includes not only being treated differently from others without a mental health problem, but also *not* being treated differently in line with people's expectations of how they feel they should be treated as a person with a mental health problem. While this distinction is already applied in some contexts – for example 'reasonable adjustments' in the workplace – this is the first study to show how this same distinction is applied by people describing discriminatory behaviours from friends and family.

Second, our study shows how discriminatory behaviours impact on individuals in different settings. In institutional settings, examples given ranged from potentially serious health complications due to reduced access to health care, to financial hardship due to cuts in welfare benefits. These impacts are, of course, those identified by participants and cannot be independently shown to be the result of actual or perceived discrimination. Nevertheless, these examples provide useful accounts of how the decisions and behaviours of others in these settings could have severe consequences. In personal settings, the main impact is the loss of emotional and practical support, with detrimental effects on people's mental health. These impacts emphasise that discrimination is not just a matter of social justice but may be a health problem in itself.

Third, it demonstrates the difficulty people have in assessing whether a behaviour is discriminatory or not. This reflects the lack of a clear and consistent understanding of discrimination. Reported behaviours vary in the motivation ascribed to discriminators (e.g. between the government's welfare benefits decisions and mental health professionals being overprotective), the behaviours themselves (e.g. diagnostic overshadowing compared to social distancing) and the impact on the participant (e.g. the emotional impact of families not understanding and the financial hardship of losing welfare benefits). Behaviours which others might ascribe to poor customer service, an individual's mood at the time or a failure in communication, could perhaps be assessed as discrimination by someone with a mental health problem, or indeed with any characteristic which has, historically, left people devalued or disrespected. It is not surprising that individuals would have this difficulty as any prejudice is

unlikely to be overtly acknowledged by the person engaging in these behaviours. It is also, however, quite possible that some of these behaviours are not the result of prejudice at all but simply of a failure to behave in the expected way.

This study has a good sample size for qualitative analysis allowing an in-depth exploration of discrimination accounts. However, further analysis into specific contexts and discrimination types is required to develop this further. Repeating the study with well-defined populations such as young people aged 16–25, Black and Afro-Caribbean men, women with postnatal depression would strengthen our work. The low response rate to the overall survey, and the underrepresentation of people with schizophrenia and bipolar disorder in the qualitative sample may indicate a bias in the participants. Nevertheless, the sampling is preferable to many other ways of recruiting to qualitative studies – such as general advertising, charity networks or snowballing – by opening the possibility of inclusion in the study to all people receiving mental health treatment in these five NHS Trusts. This helps to allow inclusion of a wider range of experiences and people from a wide range of socio-economic backgrounds.

The approach taken in this study uses a qualitative add-on to a quantitative survey. As a result, the detail collected about the examples described and the wider views and experiences of individual participants are not as rich as may have been the case in a purely qualitative study. The approach therefore gives us a wide but shallow view of these experiences, rather than a narrow but deep one. This is a limitation of the study, but we believe that this approach is nonetheless valuable in allowing the kind of comparison undertaken here.

These findings have implications for measuring and challenging mental health discrimination. There is a need to move away from viewing discrimination as a manifestation of a coherent set of prejudices in favour of more nuanced measurement of context-specific behaviours. Antistigma interventions can use these insights to help tailor messages both to people with a mental health problem and to the wider public which specifically acknowledge the range of behaviours which may be perceived as discrimination. Helping people to understand and better support others with a mental health problem, for instance, may be more effective than attempting to challenge assumptions about mental health. Equally, campaigns will have limited effect on the overall experience of discrimination unless they target a range of groups,

including health professionals (see pages xx-xx in this issue), welfare staff, policymakers and the general public.

The study also raises conceptual challenges around the understanding of the term 'discrimination'. Once this term is taken beyond a strictly legal definition, our findings suggest that it may be understood very differently by different people. It may require us to consider whether it is useful to have a term to describe behaviours which are perceived as unfair and devaluing *by the recipient of these behaviours or other observers*, beyond what is specifically proscribed by law or other codification. Limiting an understanding of discrimination to that defined in law would likely serve to undermine the everyday experiences of many people from disadvantaged or devalued groups. Readers may judge that some of the behaviours described by participants are not discriminatory, or that without knowing the motivation for behaviours, participants are wrong to assume that they are being discriminated against because of a mental health diagnosis. However, the challenge of providing a consistent but sufficiently inclusive understanding of what behaviours should be considered discriminatory is not easy, and arguably the perception of the person who witnessed the behaviour first hand may be the best insight into its nature that is ever going to be available to us. These questions reach beyond the mental health field and have implications when considering potential discrimination on the grounds of gender, race, sexuality or other characteristics.

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Declaration of interest

None.

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