A qualitative study exploring experiences of discrimination associated with mental-health problems in Ireland

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Aims. Stigma and discrimination related to mental-health problems impacts negatively on people’s quality of life, help seeking behaviour and recovery trajectories. To date, the experience of discrimination by people with mental-health problems has not been systematically explored in the Republic of Ireland. This study aimed to explore the experience of discrimination as a consequence of being identified with a mental-health problem.

Methods. Transcripts of semi-structured interviews with 30 people about their experience of discrimination were subject to thematic analysis and presented in summary form.

Results. People volunteered accounts of discrimination which clustered around employment, personal relationships, business and finance, and health care. Common experiences included being discounted or discredited, being mocked or shunned and being inhibited or constrained by oneself and others.

Conclusions. Qualitative research of this type may serve to illustrate the complexity of discrimination and the processes whereby stigma is internalised and may shape behaviour. Such an understanding may assist health practitioners reduce stigma, and identify and remediate the impact of discrimination.

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Introduction

Using mental-health services or being identified as having mental-health problems continues to carry stigma (El-Badri & Mellsop, 2007; Peterson et al. 2007; Lyons et al. 2009). Being diagnosed with mental illness frequently means taking on a tainted identity and having ones experience discredited (Goffman, 1963). Stigmatising views associated with mental illness are held by the general public (Zartaloudi & Madianos, 2010), health professionals (Jorm et al. 1999) and people diagnosed as mentally ill (Aromaa et al. 2011; Brohan et al. 2011). Stigma impacts negatively on self-esteem, compounds illness, exacerbates distress, impedes people from seeking or engaging fully in treatment (Corrigan, 2004), reduces quality of life (El-Badri & Mellsop, 2007) and gives rise to discrimination.

Discrimination is related to stigma and refers to actual experiences of being treated differently due to some defining attribute such as mental illness. Negative discrimination is a near ubiquitous experience of people diagnosed with mental illness across countries (Thornicroft et al. 2009; Rose et al. 2011). Furthermore, the rate of reported anticipated discrimination or felt stigma is even more common and impedes people from social participation that might be crucial to their recovery (Rüsch et al. 2009). The relationship between public stigma and self-stigma needs to be understood to make sense of people’s help seeking and ongoing participation in treatment (Corrigan, 2004).

There is a parallel process between stereotypical ideas about people with mental illness, prejudice (negative attributions on the basis of stereotypes) and discrimination (how people respond and behave) that
operates at a public and at an individual level. Rüsch et al. (2009) found that high self-stigma at baseline predicted hospitalisation independent of psychopathology in a sample of service users at 6-month follow-up. They suggest that this might be related to a reluctance to seek help or mobilise social coping resources. These tentative findings at least point to the importance of understanding the experience of stigma and discrimination by all those with an interest in promoting mental health.

A recent survey of public attitudes towards disability in Ireland (n = 1004) found that people viewed others with mental-health problems least favourably of all people with disabilities. How these attitudes translate into behaviour is unknown at this time. Rose et al. (2011) note that very few studies on discrimination have explored the experience of people directly affected by discrimination related to mental-health problems. This is the first study to systematically explore the discriminatory experiences of people identified as mentally ill in the Republic of Ireland.

**Aims**

This study was commissioned by Amnesty International and formed the early phase of a national study exploring discrimination in the Republic of Ireland. The aim of this phase was to undertake an in-depth exploration of people’s understanding, experience and the impact of discrimination as a consequence of being identified with mental-health problems.

**Method**

**Recruitment**

After institutional ethics approval was obtained, recruitment began and involved a number of strategies including a national advertising campaign using radio and print media, social networking sites and non-government organisations. Participants were eligible to participate if they were over the age of 18 years and identified themselves as having experienced mental-health problems. Potential respondents rang a free phone number and were provided with further information and the opportunity to ring back at a later date should they choose to participate. Those that consented to further involvement were phoned back by an interviewer and a mutually agreeable date, time and place for an interview was negotiated. Interviews typically took place in public buildings such as libraries, community halls and hotels.

The first 30 respondents were asked whether they would participate in an in-depth interview which might last between 1 or 2 hours (all consented). The interviewers sought to elicit a rich description of one or more examples of discrimination that were most significant to the individual rather than an exhaustive list of examples. A further 276 people undertook a briefer structured questionnaire exploring discrimination (reported elsewhere).

**Data collection and analysis**

A qualitative design was used. Interviews were undertaken by people who identified as having lived experience of mental-health problems. The analysis sought to reflect the reality of individuals while acknowledging that the broader social context (including the relationship with the interviewers) impinges on the meaning of experience (Scott, 2005). Transcribed interview data were subject to thematic analysis (Braun & Clarke, 2006) with the aid of the software package NVivo (‘NVivo Qualitative data analysis software,’ 2010).

Initial coding was undertaken around four areas of questioning (what discrimination is, examples, personal impact and recommendations to counter discrimination) and from that point analysis was treated inductively and focused on semantic themes. The thematic map that was generated was reviewed periodically to ascertain whether the cluster of themes or examples accurately reflected the meanings evident in the dataset as a whole (Braun & Clarke, 2006). Finally, the entire dataset and thematic map were re-read with a particular view to ensure that all variation and examples were captured by the thematic map and that themes were conceptually coherent.

**Results**

Twenty-seven of the 30 participants completed a questionnaire providing demographic information. The average age was 43 years (range 23–62 years) with 63% male. Nine people lived in Dublin, and two lived in Galway or Cork. The majority (n = 16, 59%) lived in small towns or villages. All but two people identified as Irish. The majority of people (n = 21, 77%) had a post-secondary school qualification, and eight had post-graduate qualifications. However, only five people were in paid employment. Sixteen people had incomes of less than €15,000 per year. Eight people were on sickness benefits, four were students and four were unemployed. Almost half of the participants were single and had never married (n = 13, 48%), and nine were married or in long-term relationships. Only seven people owned their own home.
Most people reported being formally diagnosed with one or more mental illness at the average age of 27 years (range 16–50). Bipolar affective disorder (n = 9) was most commonly identified, followed by major depression (n = 8). The remainder identified anxiety disorders, borderline personality disorder and schizophrenia as their last diagnosis. Fifteen people had been admitted to hospital for mental health on average 4.5 times in their lifetime. Most people reported having been prescribed various medications (antidepressants = 18, antipsychotics = 13, mood stabilisers = 13, sleeping tablets = 16, side effect tablets = 8, anti-anxiety drugs = 15). Five people had also received electroconvulsive therapy (ECT) and nine people reported receiving other treatments such as counselling or vocational rehabilitation.

This analysis attempts to convey a sense of the predominant themes drawn from over 40 hours of transcribed interviews with selected truncated quotations from respondents used for illustrative purposes. Most people provided an example of discrimination they had experienced relating to mental health that involved employment. Half the respondents described being mocked or shunned by others in personal relationships or experiencing discrimination in relation to accessing health care. At least half of individuals also spoke of a fear of disclosing mental-health problems and cited examples where such disclosure had led to negative consequences. Examples from business and finance were less often described.

Twelve participants (45%) rated that discrimination relating to mental health caused them moderate or a lot of distress. People identified a range of sources of support for mental-health problems including health professionals (n = 15, particularly general practitioners) and friends or family (n = 10). They said that these were usually also the people they would turn to if they believed they were treated unfairly. Eleven people could not list other agencies that might be of assistance if they believed they were discriminated against.

**Employment**

Work was considered exceptionally important in order to maintain well-being or esteem by most respondents. Some, for example, stated work was a place where they could maintain normality, and they noted that work was a place of refuge from other stressors, while others stated that problems at work were the most stressful to deal with and that at times their work performance was affected by mental-health problems.

People were ambivalent about declaring a history of mental-health problems when applying for jobs and a third of respondents described instances in which they perceived they had missed out on job opportunities because of mental-health problems and often with disregard for their qualifications or work history.

I’ve had bad experiences with employers mostly … I used to work as a chef… I went for a job that I was over qualified for … I was offered the job and asked to start on Monday … I told them I couldn’t because I see my psychiatrist on Monday … it changed then … he had to see a few more people … I never heard from him again … so before I had the mental illness I had the job and then once I had the mental illness the job was gone … I was definitely discriminated against. [IV3]

Often people have gaps in their employment history that may need accounting for and people are challenged to provide an honest explanation in response to direct questions.

I can’t get a job … I’ve tried and tried and tried … everything is going grand in the interview and some-one will ask you a question … there might be a gap in your employment record … they’ll say well where have you been? And I’ll say … I haven’t been that well at that point in time … ’Oh I’m sorry to hear that, do you mind if I ask you what sort of a health problem it was?’ And I’ll say ‘well I was in a psychiatric hospital because I have’ … and you can see the look and it’s all downhill … you never hear from them again. [IV6]

While some respondents stated that they received understanding and compassion from work colleagues many also described being shunned, avoided or bullied by others in the work place. Those that were in employment but had faced difficulties and disclosed them to colleagues, managers or human resource (HR) personnel had sometimes received unhelpful responses

I know the head of HR just did not know where to start dealing with me. He was kind of “Oh you have mental health problems and how do we know that you’re fixed and how do we know you’re not going to break again?” … and questions like that … where as if I had broken my leg I wouldn’t have been asked. [IV7]

People described being the object of workplace jokes and fairly overt harassment after they disclosed having a history of mental-health problems. The consequences of complaining about harassment, bullying or discrimination can make it almost untenable to remain in a workplace. One person described making a complaint about the behaviour of co-workers who subsequently were scrupulously careful about presenting a friendly public face but shunned the worker while escalating a campaign of subtle harassment.

Some people did recognise that there were times that their work performance was impaired to the extent that they needed to take ‘time out’ from work. Others chose to continue attending work knowing that their performance was impaired but nevertheless,
deriving satisfaction from it despite a lack of understanding from colleagues and supervisors.

...in the company who I worked for my performance was poor...I suppose the comments were due to that but they didn’t know the reason...I was trying to get to know a certain job...I wasn’t doing that well. My manager came over...asking my understanding of a certain thing and I obviously wasn’t showing that understanding because I was depressed that day...as he walked away I heard him say...“why doesn’t he just leave?”...it was just kind of muttered behind my ear but I still heard it...then...another manager in front of me, who I wouldn’t be responsible to...he said...quite loudly...“pure greed, pure greed”...he didn’t get it at all. [IV8]

One woman described feeling depressed after being ‘bullied’ by a co-worker and spending an hour or more each day crying in the bathroom. She opted to resign and on doing so was asked to sign a statement that the employer had made every effort to resolve the situation. However, she stated that in fact nothing had been offered or done to address the situation or offer her support. In some instances people described an inextricable relationship between relations in the workplace, work performance and mental health.Indeed, work stressors, bullying and harassment precipitated or exacerbated mental-health problems for many people.

One respondent reported having obtained higher degrees in law, engineering and journalism but being on a disability allowance for 11 years. The gaps on his curriculum vitae made it difficult to obtain employment and this person reported being told by an employment consultant that ‘no one would employ a mentally ill engineer’. Even at the height of the building boom in Ireland he reported not being able to get an interview for employment in his profession. One problem relating to employment was a lack of flexibility around work hours. He stated that the illness made it impossible to sit still in an office for 40 or more hours a week, but flexible working conditions or part-time work were not available.

Experience of mental-health problems can confer some advantages in some settings. In the mental-health industry itself, there are a limited number of paid roles available to those with experience as mental-health service users as advocates, consultants, researchers and teachers. However, such roles may be fraught with potential problems. One person who was working as a mental-health support worker was invited to co-facilitate a support group with another professional who valued sharing the role of facilitation with someone who had experience of using services.

...everybody was agreeing to it but when she mentioned my name some of the staff and particularly this psychiatrist who was my ex psychiatrist at the time said that he didn’t want that to happen, and he said it was a bridge too far...that one of his ex patients could become one of his colleagues... [IV9]

Personal relationships

Being the subject of mocking and taunting was an experience that many people had that went back to childhood and inevitably took a toll on mental health and set them apart from others:

...my illness made me very quiet and shy so you’re more susceptible to criticism or being mocked...I was never physically abused it was more subtle, comments made, snide remarks, underhand you know, it wasn’t very nice, I’ve learned to forgive them but it did happen you know, it doesn’t always have to be very obvious. [IV10]

Sometimes people supposed that harm was not intentioned, but nevertheless being pointed out as different from peers was confronting and sometimes damaging.

I’ve a tendency to blink quite a lot when I’m stressed...this girl...asked the teacher...why do people blink in a certain way?...the whole class turned around and started staring at me...and one girl who was sitting very close to me looks right at me and goes ‘look she’s doing it right now’. And that’s actually when I realized...I was doing it. And it was very hurtful... [IV4]

Verbal ‘put downs’ also extended beyond childhood and adolescence, and even if construed as good natured humour by some, could be perceived quite differently by the individual concerned and impinge on their well-being. One person described how people were drawn to them when they were elated with mood and presentation.

I would get very depressed, there would be plateau’s when it would be just like this, just sitting here chatting and my friends at the time would come in to the pub and they would expect this high person, this person who was cracking jokes and doing stupid things and if I wasn’t doing that, they’d ask ‘what the f...is wrong with you’, what’s your problem and they’d walk away. [IV11]

While many participants described friends as being supportive, several described losing friends as a consequence of being identified as having mental-health problems. As in cases of applying for jobs most participants were ambivalent about disclosing even a history of mental-health service usage to friends or acquaintances. Participants revealed elaborate ‘face management’ strategies so as not to expose themselves as vulnerable or ill.
... one of the problems I had was with the depression came the lack of energy and the lack of desire to do things ... so the weight went on and the self-esteem went lower ... people were passing comment and you couldn't really say "I'm on really heavy medication for depression at the minute" ... so you're having to keep secrets all the time ... and come up with excuses as to why you're having to behave in such a way because you don't want it out in the public domain ... [IV7]

To some extent face management strategies were successful and some people stated that few friends, acquaintances or indeed family members were aware of their problems. Others described making careful considered choices about who they would share such information with. One young male noted that it was difficult to maintain intimate relationships as a consequence of being identified as having mental-health problems.

... they wouldn't be as keen on you or as interested in you ... if you declare mental illness ... when I had a girlfriend I went into hospital and she just left me and that was it. [IV14]

Disclosure of a mental-health problem frequently changed the dynamics in relationships often for the worse. One father of children had access to his children and that was when my mother wasn’t calling me a slut and a whore and things like that ... my brother and my sisters picked up on the mental instability bit but they had no idea of the source of it ... everybody had me labeled as mentally unwell and there was no valid reason for it but my siblings didn’t know that ... [IV16]

Most participants cited examples of being misunderstood by people and noted that many people did not understand the impact of mental-health problems on behaviour. Most faced daily dilemmas regarding disclosure of mental-health problems, sharing why they made particular choices or were behaving in a particular way. As some people noted, they themselves sometimes did not understand the reasons for their behaviour but having to account for their behaviour and decisions set them apart from other people.

... I don’t drink because with my mental health problem ... medication and stuff like that ... it always comes up the question, “oh why aren’t you drinking” because I still will try to be social ... I suppose it’s a case of answering the question but not answering, you’re not giving the full answer but not being rude ... it’s more where I regularly meet the problem of my mental health being in the background ... but they not knowing about it. [IV8]

Health care

It is something of a paradox that respondents often identified particular health professionals as being supportive and immensely helpful in dealing with mental ill health but the process of care for many people was also perceived to be the source of greatest discrimination and disempowerment. Dealings with the mental-health system engendered emotive responses from many people.

A sense of injustice was a predominant theme in the stories of people who had experienced involuntary treatment.

... as a 14 yr old boy I spoke out against abuse in this country, as a 14 yr old boy and my punishment for that at the time was to be locked up in the asylum ... at 14 yrs of age ... in the ward for the insane. And when I came out ... at 15 ... I was given a ticket to go to the UK ... [IV17]
Some participants had become increasingly sophisticated in their understanding of how therapy ought to proceed and what treatments ought to be offered with respect to certain kinds of problems. They reported feeling ill at ease about simply acquiescing to treatment or deferring to authority. Some described assertively asking for particular psychological therapies.

I've been sitting in with a consultant its like you're given a label and basically anything you say about your life or difficulties none of that is discussed, its just medication. Psychiatry was neither dealing with those issues and it wasn't looking at them as important ... there is not ... reason for the medication or treatment that they use so you're given that label and then you're denied access to ... treatment ... like I had to ask specifically for the CBT [Cognitive Behavioural Therapy]. [IV21]

People noted that when they were known to have a mental-health problem their motivations, and truthfulness were questioned or at least respondents reported a sense of their credibility being challenged.

**Business and finance**

Respondents were aware that disclosure of mental-health problems could have a negative impact on earning potential. People predicted that disclosing problems with mental health could also have an adverse impact on obtaining bank loans and insurance. People stated that they are not considered a good prospect for a loan.

I went along in 1999 and I didn't declare the illness and they offered me a mortgage for 350,000 for a house in Dublin, and I was farming and I went into them there for a 1,000 after coming out of hospital and they wouldn't give me 1,000 because they knew I had a disability. [IV22]

People had a strong sense that their status as a former mental patient was used to discriminate against them even when this aspect of their history was not formally disclosed. People from smaller communities recognised that their history of 'mental-health service' usage was often widely known and while their status was rarely acknowledged they strongly suspected that this was the basis of discrimination. One man stated that he was repeatedly refused private rental accommodation in his home town despite there being vacancies, because he was not welcome.

... particular the housing piece it was the community that lived around the house that ... I was going to ... they didn't want someone going to their area that had a recognised mental health problem. [IV19]

Some who had experience in prolonged periods of hospitalisation stated that gaps on their curriculum vitae, lack of rental history (and availability of references) and poor savings histories not only disadvantaged them in terms of applying for employment, loans and private housing, but it also served to maintain people within a cycle of dependency.

It was a combination of factors such as employment history combined with mental-health service usage history that appeared to particularly disadvantaged people. Actual manifestations of mental ill-health were rarely mentioned as being the reasons for discrimination. For example, one person broke his oven and fridge soon after a lengthy hospitalisation. At a time when credit was relatively easy to obtain, and despite an unblemished credit this person was unsuccessful in obtaining credit in their home town and
Conclusions

Qualitative research of this nature has some inherent limitations. Findings cannot be generalised beyond this small cohort of people who volunteered to share their experiences. No attempt was made to exhaustively list or explore all examples of discrimination and the analysis occurred after the interviews took place which prevented exploring themes in more detail as they were discerned in the analysis. It is possible that some experiences were more significant than others and it must be noted that some experiences of discrimination may have been overlooked altogether. Analysis of this finite dataset led to an approximation of saturation (Charmaz, 2006) of some themes such as employment but the list of themes may not be exhaustive.

This study provides an exploration of some of the experiences that were particularly salient or significant to this group of people. While, this sample was a community derived, non-clinical sample, a success of the sampling strategy was that respondents volunteered having experienced a broad range of mental-health treatment experiences including medications, psychotherapy, ECT and hospitalisation. These people provided a credible, articulate and often moving account of discriminatory experiences.

Thornicroft (2006) points out that most research on the experience of stigma and discrimination has focused on the people diagnosed with schizophrenia. This study employed a diagnostically heterogeneous sample, the majority of whom had received other diagnoses. It has been found that stigmatising attitudes vary with diagnosis (Crisp et al., 2005) and discriminatory behaviour associated with particularly unusual or less explicable behaviours. However, in a focus group study of discrimination as experienced by people with a diagnosis of schizophrenia (Schulze & Angermeyer, 2003) respondents reported negative reactions from others as soon as they had a single contact with psychiatry and it was the broad identification of being mentally ill that was most stigmatising. Similarly, the kinds of experiences reported in this study did not appear to be related to diagnosis but rather a broad brush of mental illness. This may be more salient in Ireland than in other countries, as Ireland had until the 1980s, the highest number of psychiatric hospital beds per head of population in Europe (Thornicroft, 2006) and contact with state welfare institutions of many kinds (e.g. for unmarried mothers, borstals, etc.) carried a great deal of stigma. The legacy of shame associated with being confined in state institutions may persist. What may also make this Irish cohort somewhat different from other international samples was the experience of small village life for some, in which one may be known to every other person in the village. Where people may hold stigmatising views about mental illness in such environments, the experience of discrimination may be unrelenting and particularly difficult to manage.

The broad themes are consistent with the limited literature relating to discrimination and mental health. For example, in a recent survey of 785 people with self-identified mental illness in New Zealand (Peterson et al. 2007), the most commonly reported areas of discrimination were in relation to friends and family (59%), a fear of being discriminated against (46%) and discrimination in looking for employment (34%) and mental-health services (34%). Rose et al. (2011) undertook a thematic analysis of structured interviews with 75 people diagnosed with schizophrenia and found that being shunned, mocked and abused were commonly cited experiences. They also noted that respondents reported withdrawal from society to varying degrees. What this qualitative exploration adds is a greater sense and appreciation of the nature and impact of discrimination beyond its prevalence.

Participants in this study all provided concrete examples of discrimination. However, most also alluded to being unsure if they experienced discrimination as they were unclear of the motivations of other people and went to considerable lengths to conceal evidence of mental-health problems. They recounted engaging in what has been described as ‘face-work’ (Goffman, 2005) or the wilfully projecting of an image of a competent, emotionally regulated individual. Participants in many circumstances expected to be treated differently, unfairly or be discounted if mental illness or vulnerability was revealed and thus employed strategies to maintain social standing. This manoeuvring arises in part from ‘self-stigma’ or the internalisation of ideas that being mentally ill or vulnerable connotes lesser worth (Corrigan & Watson, 2002). Interestingly, Verhaeghe & Bracke (2011) concluded from a large Dutch study (n = 650) that service users are less trusting of health professionals because of self-stigma (fear of devaluation and discrimination and feelings of shame and inferiority) rather than actual discriminatory experiences. Read et al. (2006)
suggest that the promulgation of biogenetic rather than psychosocial explanations of mental illness may lead to negative attitudes towards people. There may be subtleties embedded in the encounter between health professionals and service users that reinforce stigma which participants in this study highlighted.

Health professionals may inadvertently perpetuate a discrediting of the person as a knower (Lakeman, 2010). Being identified as mentally ill was believed by some to be a means of silencing them and discrediting their testimony relating to other injustices. People expressed a sense that being identified as mentally ill was to have a different status from other patients and in various ways led to different dynamics with health care providers. Health professionals were also considered a very important source of support to this group but people did not always believe they received the help they needed or experienced the respect afforded others. It is hoped that the testimony and experiences shared by this group will assist in illustrating how stigma and discrimination relating to mental-health problems is played out and perpetuated in important spheres of people’s lives. Without addressing stigma and discrimination in its myriad of subtleties people with mental-health difficulties will continue to live less fulfilling lives.

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Declaration of Interest

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References


NVivo Qualitative data analysis software (2010). QSR International Pty Ltd: Victoria, Australia


