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Stigma- and non-stigma-related treatment barriers to mental healthcare reported by service users and caregivers

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A B S T R A C T

Delayed treatment seeking for people experiencing symptoms of mental illness is common despite available mental healthcare. Poor outcomes are associated with untreated mental illness and caregivers may eventually need to seek help on the service user's behalf. More attention has recently focused on the role of stigma in delayed treatment seeking. This study aimed to establish the frequency of stigma- and non-stigma-related treatment barriers reported by 202 service users and 80 caregivers; to compare treatment barriers reported by service users and caregivers; and to investigate demographic predictors of reporting stigma-related treatment barriers. The profile of treatment barriers differed between service users and caregivers. Service users were more likely to report stigma-related treatment barriers than caregivers across all stigma-related items. Service users who were female, had a diagnosis of schizophrenia or with GCSEs (UK qualifications usually obtained at age 16) were significantly more likely to report stigma-related treatment barriers. Caregivers who were female or of Black ethnicities were significantly more likely to report stigma-related treatment barriers. Multifaceted approaches are needed to reduce barriers to treatment seeking for both service users and caregivers, with anti-stigma interventions being of particular importance for the former group.

1. Introduction

Many individuals experiencing poor mental health do not receive treatment despite it being available in high-income countries (Thornicroft, 2008; Wang et al., 2007). Delays in receiving treatment have been associated with poor outcomes. For instance, lengthy delays in untreated psychosis can predict poorer neurocognitive ability (Amminger et al., 2002; Gaynor et al., 2009), lower quality of life (Harrigan et al., 2003), impaired social functioning (Barnes et al., 2008), longer length of first hospitalisation (Penttila et al., 2013) and are associated with neuro-anatomical changes such as decreases in brain grey matter volume (Guo et al., 2013; Malla et al., 2011). Duration of untreated illness is also associated with worse outcomes in affective disorders (Dell'Osso et al., 2013). For example, lengthy treatment delays for those with bipolar disorder can increase the risk of substance misuse (Lagerberg et al., 2010) and attempts at suicide (Nery-Fernandes et al., 2012).

Individuals who later receive a diagnosis of schizophrenia, bipolar disorder or depression may initially delay treatment seeking. Possible reasons include lack of knowledge about poor mental health symptoms or ignorance about how to access professional mental healthcare (Henderson et al., 2013). Individuals may prefer to manage the problem themselves (van Beljouw et al., 2010) or mistakenly attribute early symptoms to physical illness or lack of sleep (Tanskanen et al., 2011). Insight, or the awareness of having a mental illness, the willingness to accept treatment and the ability to conceptualise or relabel mental experiences (such as delusions or hallucinations) as pathological (David, 1990), may also be an important factor in treatment seeking. Insight is strongly associated with treatment compliance (Bitter et al., 2015) but further relates to stigma.

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The stigma associated with mental illness may act as a treatment barrier to professional mental healthcare (Gulliver et al., 2010; Thornicroft, 2008). Stigma can be considered a multifaceted concept involving: labelling; negative stereotyping; separation of ‘them’ from ‘us’; status loss and discrimination, leading to multiple inequalities (Link and Phelan, 2001). Stigma can delay treatment seeking in several ways (Corrigan, 2004; Schomerus and Angermeyer, 2008). A recent systematic review showed stigma was the fourth most frequently reported barrier to mental healthcare, with treatment stigma (the stigma attached to seeking professional mental healthcare) commonly associated with reduced treatment seeking (Clement et al., 2015). Self-stigma, or the means by which an individual accepts stigmatising views broadly held by others, may also deter treatment seeking. For instance, individuals with high levels of insight who accept self-stigmatising beliefs about mental illness may have lower levels of self-esteem and hope for the future (Lysaker et al., 2007). Low self-esteem and self-efficacy can accompany self-stigma and individuals may feel dissuaded from accessing or using practices which would facilitate social inclusion and recovery (Corrigan et al., 2009).

Delaying treatment seeking may risk the individual's health deteriorating until they become too ill to seek help for themselves, resulting in adverse pathways to care such as via the emergency services, social services or the criminal justice system (Singh and Grange, 2006). These pathways often result in involuntary treatment which is undesirable because it is associated with symptoms of post-traumatic stress disorder through the potential iatrogenic effects of psychiatric care (Tarrier et al., 2007), a reluctance to seek future treatment (Swartz et al., 2003) and higher economic costs (Cheung et al., 2013; Sharac et al., 2010). Consequently, individuals may benefit from an informal caregiver seeking help on their behalf.

A caregiver can be defined as any person who provides unpaid support for an individual who is unable to cope without this support (Carers Trust, 2014). This is usually a parent, partner, close friend or relative of the individual with a mental health problem and there are few difficulties in identifying who this person should be (Szmukler et al., 2003). Family member or close friend involvement is associated with shorter treatment seeking delays and avoidance of adverse pathways to care (Cole et al., 1995; O'Callaghan et al., 2010). However, early symptoms of mental illness are often vague and potential caregivers may have difficulty recognising these or may mistakenly attribute them to teenage difficulties, increased drug use or stress (Kuipers, 2010). Caregivers also report a lack of knowledge about mental health services, including not knowing that these services exist (Tanskanen et al., 2011).

In summary, existing research suggests treatment seeking may be delayed by the service user or by the caregiver. However, previous qualitative research indicates treatment stigma is of more concern for service users than for caregivers (Tanskanen et al., 2011). The extent to which caregivers are deterred by stigma in seeking treatment is unknown.

The present study objectives were to:

1. Establish the frequency of stigma- and non-stigma-related treatment barriers to mental healthcare reported by: service users with diagnoses of schizophrenia spectrum disorders, bipolar disorder or major depression; and caregivers in accessing care on behalf of a service user.
2. Compare the barriers to mental healthcare reported by service users and caregivers.
3. Investigate demographic and clinical variables associated with stigma-related treatment barriers to mental healthcare as reported by service users and caregivers.

2. Method

This study was undertaken within the wider MIRIAD (Mental Illness-Related Investigations on Discrimination) study (Farrelly et al., 2014). MIRIAD was a large cross-sectional study of 202 individuals using secondary mental health services and 80 caregivers in south London which aimed to increase understanding about the nature and effects of discrimination because of mental health problems. Data were collected between September 2011 and October 2012. The study received ethical approval from the East of England/Essex 2 Research Ethics Committee (Ref 11/EE/0052).

2.1. Inclusion criteria

Inclusion criteria for service users were: aged at least 18 years; a clinical diagnosis of either major depression, bipolar or schizophrenia spectrum disorders (ICD-10 F32, F31 and F20-F29 respectively); current treatment with a community mental health team; sufficiently fluent in English to provide informed consent; sufficiently well for participation to not pose a risk to their or others' health or safety (as determined by their clinicians' clinical judgement); and one of the following self-defined ethnicities: Black (Black African, Black Caribbean, Black British or other Black background), White (English, Welsh, Northern Irish, Scottish, British, Irish, Irish traveller or other White background) or Mixed (White and Black Caribbean, White and Black African or other multiple ethnic background) ethnicities. Recruitment took place within ethnically diverse areas of south London with similar or higher levels of deprivation than the England average (Public Health England, 2015). Approximately 55% of the population here are of White ethnicities, 25% of Black ethnicities and 20% of Mixed, Asian or other ethnicities (Office for National Statistics, 2011). We did not include Asian ethnicities due to low prevalence numbers in the study location.

Inclusion criteria for caregivers were: aged at least 18 years; main caregiver (defined as the person who could potentially seek help of any kind on behalf of the service user or potentially assist the service user to seek help of any kind); and sufficiently fluent in English to provide informed consent. The caregiver may or may not be supporting a service user in the study.

2.2. Recruitment

Service users were recruited from 14 community mental health teams. Staff in the community mental health teams were approached for their approval to participate in the study and lists of service users who met inclusion criteria were presented to clinicians. Clinicians were asked if the service user was sufficiently well not to pose a risk to themselves or others and, if so, a letter was posted to the service user inviting them to contact the research team if they were interested in participating. This letter was followed-up by a reminder flyer if there had been no response within one month.

Caregivers were recruited via two methods. Firstly, MIRIAD service users were asked if they had a primary caregiver and, if so, the service user sought their caregiver's permission for their contact details to be passed onto the MIRIAD team. Secondly, caregivers were recruited from six caregiver support groups linked to the mental health teams from which the MIRIAD study was recruiting. These caregivers were informed about the study before researchers attended the group by an invitation letter.

2.3. Data collection

Consenting service users were interviewed by Research Workers. Interviews were spread over two sittings (range 1–4) and service users received £15 per sitting for their time. The interview schedule collected demographic and clinical information and contained a range of measures; those relevant to this paper are detailed below. Clinical data were also extracted from electronic patient records with participant consent (see Table 1). Consenting caregivers completed the survey either online, via telephone interview with a Research Worker or by postal survey. They received a £10 shopping voucher for their time. No clinician or clinic received payment where recruitment took place.

2.4. Measures

Barriers to Care Evaluation (BACE, (Clement et al., 2012)): a scale developed to provide a comprehensive assessment of mental healthcare access barriers reported by people with mental health problems. Respondents are presented with items describing possible barriers which may have stopped, delayed or discouraged them from seeking or continuing with professional care for a mental health problem. There were four response categories: ‘not at all’ (0), ‘a little’ (1), ‘quite a lot’ (2), ‘a lot’ (3). The measure has a stigma-related treatment barriers subscale and psychometric analyses demonstrate that this has good reliability, validity and