Stigma and Access to Care in First-Episode Psychosis

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Abstract

Aim:
Mental health-related stigma is considered a significant barrier to help-seeking and accessing care in those experiencing mental illness. Long duration of untreated psychosis is associated with poorer outcomes. The impact of stigma on the duration of untreated psychosis, in first-episode psychosis remains unexplored. To examine the association between mental health-related stigma and access to care in people experiencing first-episode psychosis in Birmingham, UK.

Methods:
We collected data on a prospective cohort of first-episode psychosis. The Stigma Scale was used as a measure of mental health-related stigma, and Duration of Untreated Psychosis as a measure of delay in accessing care. We performed logistic and linear regression analyses to explore the relationship between mental health-related stigma and duration of untreated psychosis, adjusting for sex, age, educational level, religion and ethnicity.

Results:
On the 89 participants included in this study, linear regression analysis revealed that overall stigma and the discrimination sub-factor were significant predictors of longer duration of untreated psychosis, whilst logistic regression identified the disclosure sub-factor to be a significant predictor of longer duration of untreated psychosis.

Conclusions:
These findings demonstrate that stigmatising views of mental illness from the patient's perspectives can result in delayed access to care. This emphasises the importance of tackling mental health-related stigma to ensure early treatment and improved outcomes for people experiencing first-episode psychosis.

Key Words:
early intervention, first episode psychosis, help-seeking, psychosis, stigma

Introduction

Stigma is defined as the negative evaluation of a person as tainted or condemned on the basis of characteristics such as mental disorder or physical disability (Goffman, 1963). Stigma can be a barrier for individuals who experience psychiatric illness by making them hesitant to help-seek due to the fear of being labelled and discriminated against (King et al, 2007). Stigma has been reported as an important barrier to help-seeking, with disclosure and worries about confidentiality being the strongest elements of the stigma barrier (Clement et al, 2014; Mojtabai et al., 2011; Thornicroft, 2008).

A small number of studies have assessed this relationship specifically in first episode psychosis (FEP), with a substantial proportion of literature being qualitative (Connor et al., 2016; Ferrari et al., 2015; Stewart, 2013; Anderson et al., 2013; Chen et al., 2014; Welsh & Tiffin, 2012). A recent systematic review of mental-health stigma and pathways to care in FEP or at-risk populations revealed only nine quantitative articles with no study exploring the relationship between stigma and help-seeking from a patient perspective in FEP (Gronholm et al., 2017). Much of the literature was found to focus on family members or carers viewpoints (Compton & Esterberg, 2005) or on at-risk populations (Xu et al., 2016; Rüsch et al., 2014). These studies presented disparate findings, either reporting insignificant results or a negative association between stigma and help-seeking with small to moderate effect sizes.

We aimed to fill this important gap in the literature, by examining how mental health-related stigma influences help-seeking in FEP. We used Duration of Untreated Psychosis (defined as the time interval between onset of definite positive psychotic symptoms and commencement of appropriate treatment) as a measure of delay in accessing help. Specifically, we sought to examine whether particular aspects of stigma (i.e. external stigma through discrimination, internal stigma through disclosure) (King et al., 2007) posed a barrier to accessing care. We hypothesized that higher self-rated perceptions of stigma would be associated with delayed access to care.

Method

Participants

This study was part of the NIHR funded ENRICH Programme Grant and the methodological details have been reported elsewhere (Singh et al., 2013). Briefly, patients were recruited from the Birmingham and Solihull Mental Health NHS Foundation Trust (BSMHFT) Early Intervention Services, over a two-year period (2008-2010). Each eligible participant's community psychiatric nurse (CPN) was approached to determine whether the patient was well enough to take part in terms of symptoms, general well-being and recovery. If the CPN felt that the patient was suitable, the information sheet and consent form were given to the CPN to give to the patient. If the patient agreed to meet the research team, a researcher contacted the patient to explain the study and answer any questions. 132 patients participated in the project (45 White, 35 Black, 43 Asian, 9 'Other', age range from 14-37 years). 89 participants were included in the current study, as the remaining participants did not have complete data on our study measures. There were no significant sociodemographic or clinical characteristics between the included and excluded participants. Written consent was attained from adult participants, and parents provided consent for participants considered minors. Full ethical approval was obtained from the Warwickshire Research Ethics Committee (WREC) and the Birmingham and Solihull Mental Health NHS Foundation Trust's (BSMHFT) Research and Development Department. Ethnicity is defined as the state of belonging to a social group that has a common national or cultural tradition.

Procedure

Once consent was received, time, date and location were agreed between the research team and participant. Patient's medical records were firstly screened by the researchers to create the NOS timeline. Permission was granted by participants whether the NOS interview could be audio taped. If the patient declined, one researcher would conduct the assessments and the second researcher would write comprehensive notes. The order of assessments were as follows: (1) sociodemographic data; (2) Nottingham Onset Schedule (Singh et al., 2005); (3) The Stigma Scale (King et al., 2007).

Measures

Sociodemographics: Data was collected on age, ethnicity, religion, religious practice, birth place, marital status, living status, employment status, education level, and current diagnosis.

The Stigma Scale: A 28-item measure with established psychometric properties, on a 5-point Likert scale (Strongly Agree = 4, Strongly Disagree = 0) (King et al., 2007). The scale distinguishes three forms of stigma: (1) discrimination (external form of stigma, the experience of negative responses of other people due to mental illness); (2) disclosure (internal form of stigma, how the individual manages information about their illness); (3) positive aspects of mental illness (how individuals accept their illness).

The Nottingham Onset Schedule (NOS): NOS is a short, guided interview and rating schedule that establishes the chronology of psychosis onset (Singh et al., 2005). Three distinctive illness phases are derived from the NOS: (1) prodrome; (2) duration of untreated psychosis (DUP) (period from first psychotic symptom to treatment compliance); (3) duration of untreated illness (DUI) (period from prodrome onset to treatment compliance). This measure has high test-retest and inter-rater reliability (Singh et al., 2005). The current study used DUP, which was measured as both a continuous (number of days) and categorical (short/long) variable.

Outcome

DUP: We used both the continuous (days) and categorical (short/long) version of DUP as distinct analyses. We used both continuous and binary outcome measures due to our use of regression analysis (see below). Linear regression of continuous data is advantageous as it maximises sensitivity and thus statistical power but is limited in detecting non-linear relationships. Logistic regression may be more limited regarding statistical power but is better suited to detecting non-linear relationships. The binary version of DUP was calculated by the overall median. The median DUP for the overall sample was 357 days (11.9 months). The group was split into two DUP groups (long = > 357 days; short = ≤ 357 days).

Management of potential confounders

Adjustments for potential confounding variables were conducted in two stages. Firstly, adjustments were made for clinical and sociodemographic characteristics that have shown previous associations with stigma, such as age (Sirey et al., 2001) (continuous), gender (Chandra & Minkobitz, 2006) (categorical), and education level at time of assessment (Golberstein et al., 2008) (categorical data: school education; college education; further education). In the second stage, adjustments were made for ethnicity (Wong et al., 2017) (categorical data: White British; Asian; Black; Other) and religion (Eisenberg et al., 2009) (categorical data: Christian; Muslim; other; none).

Statistical Analysis

Exposure values that were not normally distributed were natural log-transformed. Resultant variables were standardized (Z-transformed) so the odds ratios (ORs) of logistic regression analysis represent the increase in risk of DUP per SD increase in exposure.

First, univariable Pearson's correlation analyses were performed on stigma measures and DUP (continuous and categorical). We then completed multi-variable analyses with adjustments on stigma measures showing evidence of main effects for either the continuous or binary measure for DUP. The total stigma score and associated sub-scales were assessed in separate analyses to prevent the effect of likely collinearity between stigma measures in the same model.

For the multi-variable analysis of the continuous measure for DUP/DUI, linear regression analyses were performed with and without adjustments. β-values are presented with standard errors (S.E.'s) and the significance value (p-value). For the multi-variable analyses of the binary measure for DUP, ORs and 95% confidence intervals (95% C.I.'s) were estimated using logistic regression, before and after adjustments. Statistical analysis was completed using IBM SPSS Statistics 24.0.

Results

Table 1 outlines the sociodemographic details of our included participants. Overall, the average age of the sample was 23.2 years (SD 5.2). The sample was 72% male, and 32% of the sample were White British in ethnic origin. The median DUP across the entire sample was 352 days. Across the entire sample, the average time in treatment prior to assessment was 2.3 years (SD 2.7). Across the whole sample, the mean total stigma score was 1.7 (SD 0.5). Regarding sub-scales, the mean score for disclosure was 2.02 (SD 0.7), the mean score for discrimination was 1.5 (SD 0.7), and the mean score for positive aspects was 1.6 (0.7).

Using Pearson's correlation analysis, we found significant positive correlations between the total stigma score and DUP (continuous) (r = 0.276, p = 0.009); discrimination and DUP (continuous) (r = 0.272, p = 0.010), and disclosure and DUP (categorical) (r = 0.253, p = 0.017).

Table 2 displays the results of linear regression analyses between the stigma measures showing evidence of main effects and DUP (continuous), both unadjusted and with step-wise adjustments for age, sex, education, and then ethnicity and religion in addition. Both total stigma and the discrimination sub-factor remained significantly associated with DUP following adjustments. Adjustments did not significantly adjust the strength of association.

Table 3 displays the results of logistic regression analyses between the stigma measure showing evidence of main effects and DUP (categorical, both unadjusted and with step-wise adjustments for age, sex, education, and then ethnicity and religion in addition. The disclosure sub-factor remained significantly associated with DUP following adjustments. Adjustments did not significantly adjust the strength of association.

Discussion

We examined the relationship between stigma and delay in accessing care, as measured by DUP. In doing this, we have set out to explore an area of research that has received relatively little consideration, yet is essential to improve the outcomes for those with FEP. We present several findings of note.

Linear regression analyses revealed that general mental-health related stigma, and its sub-factor of discrimination were significant predictors of DUP, even after adjusting for possible confounders. This is in line with the previous literature that has explored stigma and mental illness more broadly (Clement et al., 2014; Thornicroft., 2008) and qualitative papers that have observed this relationship in FEP (Anderson et al., 2013; Chen et al., 2014; Ferrari et al., 2015; Stewart, 2013). Discrimination in this study refers to the participant's perception of experiencing stigma, and may relate to lack of employment opportunities and negative reactions from others, including health professionals, family members, and the criminal justice system. Previously, psychotic disorders have been considered one of the most highly stigmatised conditions, with the public perceiving those with psychosis to be "violent and erratic" (Thornicroft, et al., 2009). The "Changing Minds" campaign in the U.K. has sought to reduce the negative stereotypical perceptions of mental illness through education and normalization, and research has shown the campaign to be effective (Thornicroft et al, 2013). Despite these positive changes, our findings suggest that participants' perceived discrimination remained a barrier to care access. Perceived discrimination has previously been linked to poorer physical and mental health outcomes (Pascoe et al, 2009).

Disclosure is related to a form of internal stigma, and has received empirical support in previous papers for its impact for delayed help-seeking in mental health more generally (Clement et al., 2014). Concerns regarding disclosure can be experienced in the absence of direct discrimination. An individual may not want to disclose their illness to others due to internalised negative feelings such as fear and shame, and a wish to avoid potentially unpleasant scenarios. Disclosure has been considered one of the most prominent forms of stigma as a barrier to help-seeking (Vogel et al., 2007). Our research provides further evidence that disclosure is a significant predictor of DUP even after adjusting for multiple possible confounders. That this result was present in the logistic regression analysis but not the linear regression analysis may suggest that this association is non-linear. Future research may seek to further examine this finding. These results substantiate the modified labelling theory of mental illness (Link et al., 1989) which proposes that an individual's anticipation of being labelled has a substantial negative affect. In turn, these expectations can lead to individuals socially isolating themselves, which may translate to a delayed access to appropriate care.

However, there are several limitations that should be considered when interpreting our findings. As a cross-sectional study, we were unable to determine causation or direction of association. Reverse causation is possible, in that a longer DUP could lead to higher levels of stigma. Future longitudinal studies can help explore this issue. Furthermore, there are a multitude of factors that can cause a delay in access to care, and stigma may be one small factor within a wider range of influences. Therefore, we cannot conclude that stigma by itself acts as a barrier to help-seeking. Furthermore, stigma is a complex factor with many facets. Although we were able to measure three categories of stigma from the scale used in the current study, and using a more comprehensive scale than has been used in previous studies, there could be other stigma-related issues that have an effect that we were unable to identify. For example, previous literature has measured other facets of stigma including treatment stigma, anticipated stigma, and endorsed stigma (Clement et al., 2014). Other

researchers have described the impact of stigma as two-fold: public stigma and self-stigma (Corrigan & Watson, 2002). Despite public stigma and self-stigma resembling the categories used in the current study of discrimination and disclosure, there remains a disparity of nomenclature which arguably is hampering a clear picture of the effects of stigma on mental illness.

An important potential confounder to consider is in relation to the time of assessment. We were unable to ascertain from the available data how long participants had been under the care of EI services when they were enrolled into the study and assessed, though in the U.K., EI services are available to patients for three years maximum. It is possible that perceptions of stigma may evolve over time, both over the course of illness and during the course of treatment. It is however less likely perhaps that more stigmatising views of mental illness are formed during treatment in EI services, though this would be an uncomfortable finding if it were the case. Future research therefore should seek to take this into account.

Additionally, we used DUP as a broad measure of delayed access to care. However delays in access to care may not solely relate to a patient's delay in presenting to a health professional. Delays in care can also arise from delays in referral to specialist services from a general practitioner, or from delays in receiving care within the mental health system. Our current study did not differentiate between these factors. Future research may seek to take these factors into account, as well as potentially incorporating a longitudinal aspect to research of stigma in psychosis. This may allow new insights into identifying where perceived stigmatization occurs during the journey from first symptom to treatment.

Furthermore, examining stigma-related effects and experiences through quantitative methodologies could be considered challenging, as the impact of stigma on processes along pathways to care is expected to contrast between individuals and help-seeking circumstances. Utilising a mixed-methods approach might be better suited in order to identify context and person-dependent changeability in relation to stigma (Link et al., 2004). Through a mixed-methods approach we can gather a richer, multi-faceted, and complete understanding of this relationship.

It is important to note that delayed access to care could be a result of the stigma experienced by family members and close social networks. Qualitative studies on mental health stigma from ethnic minority groups were more likely to include subthemes relating to 'stigma for family' (Clement et al., 2014). Further studies have indicated that family and social networks play an integral role regarding stigma and eventual help-seeking behaviours. Family and friends can induce and endorse their own stigmas, which can result in a delayed access to care (Lindsey & Nebbit, 2010).

Despite the potential methodological drawbacks, our study has a significant strength in that it makes a unique contribution to the existing literature, through being the first quantitative study to explore stigma in FEP from the patient's perspective. We were also able in our analyses to control for a number of relevant confounders. Our findings have implications for clinical practice. The Changing Minds campaign has sought to reduce external forms of stigma such as discrimination, though education and normalization. Our results may suggest a role also for healthcare professionals working in early intervention services in addressing the internalised stigma that may exist within individual patients. Helping individuals understand internalised stigma and its effect on disclosure, and offering means to overcome it might aid in the utilization of mental health services for those who tend to resist the use of these facilities until crisis, such as BME communities.

Conclusion

Stigma towards individuals labelled with a mental illness can act as a substantial obstacle to the recovery and provision of care for many people experiencing psychiatric problems. Psychosis is traditionally one of the most stigmatised of these conditions, being previously labelled with traits such as hostility and violence, a deficiency in self-control and irrational behaviour, as well as an amplified desire for social isolation. Our study contributes to current literature, and demonstrates that high levels of stigma belief can result in delayed access to care. It is recognised that those who enter services late may be impacted by poorer recovery and outcomes, both in the short- and long-term. It is therefore imperative to tackle the large burden of mental health-related stigma that may be perceived by patients in order to provide the best outcomes for those with psychosis. This can be achieved through educational campaigns for the general public, informing people on how to identify symptoms of mental illness in a friend or family member, and promoting a better understand of different mental illnesses and how to treat them. Additional interventions need to be developed at patient level, to address individual internalised stigma and disclosure concerns.

Conflict of Interest

The authors have no conflict of interests to declare.

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Table 1. Sample Characteristics

Variable		Duration of Untreated Psychosis (DUP) Mean (SD) or n (%)		Test Statistic p-value[1]
		Short	Long	
Age (mean years)	At assessment	22.3 (4.8)	22.8 (5.1)	0.65
	Onset	21.4 (4.8)	19.0 (5.1)	0.69
Assessment lag[2]		0.8 (0.3)	2.9 (1.2)	<0.01
Sex (n)	Male	30 (35)	31 (36)	
	Female	13 (15)	12 (14)	0.81
Ethnicity (n)	White British	20 (23)	15 (17)	
	Asian	10 (12)	17 (20)	
	Black	9 (11)	7 (16)	
	Other	4 (5)	4 (5)	0.43
Religion (n)	Christian	15 (17)	15 (17)	
	Muslim	10 (12)	15 (17)	
	Other/None	18 (21)	13 (16)	0.28
Education (n)	School level	24 (56)	24 (56)	
	Further education	19 (23)	17 (20)	0.80

[1]categorical variables (sex, ethnicity, religion, education) compared using chi-square; continuous measures (age, assessment lag) compared using independent t-test

[2]Assessment lag was calculated as a mean of the participant age of onset subtracted from the age at assessment

Table 2. Linear Regression Analysis for Stigma and Duration of Untreated Psychosis (DUP)

Predictor		Regression Co-efficient (S.E.) for DUP								
		Unadjusted Model			Adjusted for age, sex, education[1]			+ ethnicity & religion[1]		
Stigma Measures	N	β (S.E.)	r^2	p	β (S.E.)	r^2	p	β (S.E.)	r^2	p
Total Stigma	89	0.271 (0.09)	0.281	0.009	0.286 (0.08)	0.301	0.008	0.283 (0.07)	0.306	0.009
Discrimination	89	0.272 (0.09)	0.275	0.010	0.283 (0.07)	0.299	0.008	0.280 (0.09)	0.309	0.010

[1] No adjustment variable showed evidence of main effects in the models

Table 3. Logistic Regression Analysis for Stigma and Duration of Untreated Psychosis (DUP)

Predictor		Odds Ratio (95% C.I.) for DUP (Binary)								
		Unadjusted Model			Adjusted for age, sex, education[1]			+ ethnicity & religion[1]		
Stigma Measures	n	OR (95% C.I.)	r^2	p	OR (95% C.I.)	r^2	p	OR (95% C.I.)	r^2	p
Disclosure	89	2.16 (1.13 - 4.13)	0.213	0.020	2.09 (1.07 - 4.08)	0.234	0.032	2.10 (1.05 - 4.22)	0.252	0.036

[1] No adjustment variable showed evidence of main effects in the models