Bipolar disorder

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Bipolar disorder: Prevalence, help-seeking and use of mental health care in England. Findings from the 2014 Adult Psychiatric Morbidity Survey

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Abstract

Background: To date, the lifetime prevalence of Bipolar Disorder (BD) and BD patients' access to mental health care in England has not been systematically studied.

Methods: We used data from the Adult Psychiatric Morbidity Survey 2014 (N=7546). The Mood Disorders Questionnaire (MDQ) was used to screen for BD. Associations between sociodemographic and clinical variables and use of mental health services were investigated. Weighted regression modelling established factors associated with being in receipt of care for mental health problems over the last year.

Results: The lifetime prevalence of BD in the community in England was 1.7%. Approximately 40% had not received mental health care in the last year, and only 16.9% had received BD specific treatment. 14.6% had asked for a specific form of help but not received it. Psychopathology differed between individuals who successfully sought care and those who didn't. Obtaining care was independently associated with female sex (p<0.0001, odds ratio(OR):4.65 (Confidence Interval (CI):2.18-10.30), unemployment (p=0.02, OR: 2.65 (C.I: 1.23-5.88) and suicidal ideation (p=0.04, OR: 3.36, (C.I: 1.04-10.89).

Limitations: The MDQ is less sensitive than some of the longer measures, especially in the general population. Some between-group comparisons may have suffered from limited power.

Conclusions: The lifetime prevalence of BD in England was similar to rates worldwide. Most people with BD had not received any specific treatment for the condition in the last year, while 1 in 7 had requested specific help but did not receive it. Secondary mental health services in England for BD appear suboptimal.

Keywords: Bipolar disorder; Mental health care; Prevalence; Epidemiology; Household survey

1. Introduction

Bipolar disorder (BD) is a relatively common, yet highly complex mental illness (Rowland & Marwaha, 2018). Although the frequency of episodes and severity of symptoms vary both between and within individuals, it can be a debilitating and lifelong disorder contributing to significant personal suffering, functional impairment and disease burden. The World Health Organisation ranks BD as one of the most common causes of disability worldwide (World Health Organisation, 2004), and people with BD are impacted by significant rates of unemployment (Marwaha et al., 2013), comorbidity and early mortality (Crump et al., 2013; Weiner et al., 2011) due to suicide or cardiovascular disorders. In the UK, the annual National Health Service costs of BD have been estimated at £342 million at 2009/2010 pricing (Young et al., 2011) and the full economic cost of BD was £5.2 billion in 2007 (Pari et al., 2014).

Depending on which part of the bipolar spectrum is considered, results from the World Mental Health Surveys suggest a point prevalence of around 1-2% in adult populations, but there was no English centre or data from anywhere else in the United Kingdom in this survey (Merikangas et al., 2011; Pini et al., 2005). Despite comparable prevalence of BD to that of other serious mental illnesses, it may take 6-10 years after the initial onset of BD symptoms for patients to receive an accurate diagnosis and start treatment (Dagani et al., 2017; Drancourt et al., 2013). Moreover, around 1 in 4 individuals with BD have never sought treatment of any kind (NICE, 2015). These findings may reflect a failure to present for help, a lack of access to treatment, or treatment refusal. These potential failures represent a missed opportunity to ameliorate the associated suicidal thinking (Simon et al., 2007; Valtonen et al., 2005), substance misuse (Post & Kalivas, 2013), and comorbidity with other mental and physical health problems commonly seen in people with BD.

To our knowledge, there has been no previous systematic study of the community lifetime prevalence of BD in England (or the rest of the UK) or of access and use of mental health services. Analysis of data from the Adult Psychiatric Morbidity Survey in 2014 is an opportunity to address this. There is some previous evidence from the United States indicating that BD is often underdiagnosed and inappropriately treated, with more frequent use of various primary and secondary healthcare services by individuals screening positive for

BD compared to those screening negative (Frye et al., 2005). In order to plan and deliver accessible and efficient services we need to understand how frequently people with BD use mental health services, and to identify the factors linked to help-seeking, access to care, and refusal of care when requested. From the literature, we identified factors that might be linked to help-seeking in this population and used them to develop our analytic strategy. These included both demographic and clinical factors (Bhugra & Flick, 2005; du Fort et al., 1999; Wang et al., 2005) that were most relevant to BD, such as the presence of psychotic and other mood symptoms.

The aims of this study are: 1) To describe the lifetime prevalence of probable bipolar disorder in the community in England; 2) To quantify the proportion of people with probable BD in the community in contact with health services and also those requesting but refused specific forms of care; and 3) To identify the factors associated with accessing care.

2. Methods

2.1. Data collection and sample

We used data from the Adult Psychiatric Morbidity Survey (APMS) 2014, a general population survey of adults living in private households in England. Other parts of the UK were not covered in the APMS 2014. It was designed to be representative of the whole national population, and full details of survey methodology, including how weighting was carried out for selection and non-response to achieve representativeness, can be found in Byron et al (Byron, 2016). Ethical approval for the study was obtained from the West London National Research Ethics Committee (reference 14/LO/0411) and participants gave informed consent. In brief, APMS 2014 adopted a multi-stage stratified probability sampling design based on primary sampling units derived from postcode sectors (a postal sector contains about 2,550 delivery points). This was followed by the sampling of addresses within these units. One adult aged 16 or over was randomly selected for interview in each eligible household, and the final dataset consisted of a comprehensive list of measures (over 1,000 variables) from 7,546 individuals.

2.2. Bipolar disorder assessments

The Mood Disorder Questionnaire (Hirschfeld et al., 2000) (MDQ), a 13 item (Yes / No) assessment scale designed for self-completion, was used to identify bipolar spectrum disorders (i.e. BD types I, II, not otherwise specified and Cyclothymia) by the assessment of lifetime manic symptoms. In order to screen positive for BD, at least 7 items on mania / hypomania must be endorsed, together with affirmative answers regarding symptoms occurring at the same time and moderate to severe functional impairment. Originally developed and validated using a psychiatric outpatient sample, the MDQ has a sensitivity in the general population of 0.28 and a specificity of 0.97 (Hirschfeld et al., 2003) to identify bipolar disorder. This means that individuals screening positive on the MDQ are very likely to have the disorder. We therefore use the term 'probable BD' in this study. Follow-up clinical diagnostic assessments for BD were not carried out in the APMS 2014 survey.

Pre-existing diagnosis of BD: Participants were asked whether they already had a professional diagnosis of BD that has been present in the past year as a binary variable. This does not denote new diagnoses/incidence of BD; rather, the question is about whether participants have already had a diagnosis present during the past year.

Current medication for BD: This was obtained by showing participants cards listing the names of relevant medications, which included a number of antipsychotics, as a binary variable.

2.3. Help-seeking and access to care

Receipt of care: The binary variable 'anyhlca' was selected as the key indicator of care and/or treatment received for mental and emotional problems in the last 12 months. This was defined as having had any kind of mental healthcare including but not limited to attending hospital, either as an inpatient or outpatient, for a mental health reason, or discussing a mental health problem with a GP, psychiatrist, psychologist or any other healthcare professionals.

Requested care but not receiving it: This was assessed by the binary variable 'CC3Y1': 'asked for but did not get specific treatment', where specific treatment was defined as psychological therapy and/or psychotropic medication in the last 12 months.

Community service use: Participants were asked whether they had specifically seen a psychiatrist, a psychologist, or a community psychiatric nurse (CPN), or used mental health-related self-support groups in the community in the last 12 months.

2.4. Explanatory clinical measures

Psychotic symptoms in the past year: These were determined in the APMS by asking about paranoid ideation, hallucinatory experiences and first-rank symptoms (e.g. thought insertion) using the Psychosis Screening Questionnaire (PSQ; (Bebbington & Nayani, 1995)). In our study, only two narrowly defined psychotic symptoms (persecutory delusions and auditory-verbal hallucinations) were chosen, and 'unsure' responses were taken as negative. This was a binary variable, and those who endorsed the narrowly defined psychotic symptoms would have also endorsed a previous question of more broadly defined paranoid ideation and general hallucinatory experiences. We chose the narrowly defined variables because these were the strongest possible indicators of psychotic symptoms rather than other nonclinical psychotic-like experiences. Conversely, those who did not endorse the narrowly defined psychotic symptoms would not have endorsed the broadly defined experiences in the first place, as such these individuals without answers to the secondary questions were treated as having answered negatively.

Borderline personality disorder: Participants answered questions regarding lifetime personality disorder using the self-completion Structured Clinical Interview for Diagnostic and Statistical Manual for Mental Disorders, Version IV (DSM-IV) Personality Disorders (SCID-II): we used borderline personality disorder (screening positive) as a binary variable.

Depressive episode in past two weeks: This was measured by the composite score for a depressive episode variable using the Clinical Interview Schedule-Revised (CIS-R) (Lewis et al., 1992). This was a binary variable and is equivalent to an ICD-10 diagnosis of depressive episode.

Suicidal ideation in the past year: Participants were asked directly if they had contemplated suicide, and whether or not they had acted on these thoughts ('Have you ever thought of taking your life, even though you would not actually do it?'). This was a binary variable.

2.5. Socio-demographic assessment

Age group (in 10-year increments), sex (male / female), education level (higher education / secondary school / other), employment status (employed / unemployed / economically inactive), living condition (living alone or with others, including married couples, those cohabiting and single parents with children) and ethnic group (white / non-white) were included as confounding variables in the statistical analyses.

2.6. Statistical analysis

All data analyses were performed using the -survey- packages in the programming language R (Version 3.6.0 in a Microsoft Windows environment). We divided individuals who screened positive for BD into those who had received some form of care for mental health problems in the last 12 months (including current care) and those who had not. Analyses were weighted using weights provided in the dataset to account for selection probabilities and non-response, and to ensure results were representative of the general population.

Descriptive statistics were obtained in relation to all sociodemographic and clinical variables, and appropriate Chi-squared tests with weights were carried out between the categories. We also derived descriptive statistics and weighted Chi-squared tests relating to the presence of depressive episode (as measured by the CIS-R), borderline personality disorder, psychotic symptoms (narrowly defined persecutory delusions and auditory-verbal hallucinations) and suicidal ideation in the last year.

Multivariate regression modelling was then completed to establish the demographic and clinical factors associated with being in receipt of any care for mental health problems over the last 12 months in people with probable BD. For the regression analyses, being economically inactive (including students, long-term carers and those in early retirement) and unemployed were combined into a 'not in employment' category. We adopted a two-stage

logistic regression modelling process, providing odds ratios (OR) for ease of understanding. Sociodemographic variables shown from the univariate analyses to differ significantly between those with and without care (weighted Chi-squared tests) were entered as explanatory variables in Stage 1 of the model, whereas in Stage 2, the explanatory variables comprised clinical symptom scores in addition to sociodemographic variables. The outcome variable was the receipt of care for mental health problems in the past 12 months.

3. Results

3.1. Sample characteristics

The prevalence of screen positive (probable BD) for BD in the APMS 2014 survey was 1.72% (*N* = 130). Upon cross-tabulating the whole sample, we discovered that 29 individuals who did *not* screen positive for BD by the MDQ did in fact have a professional BD diagnosis present. We did not complete any further analysis of this group. Of those with probable BD as indicated by the MDQ, there was a higher proportion of female sex (55.4%), younger adults (approximately 60% were below the age of 45) and people of white ethnicity (87.7%). More females also received a professional diagnosis of BD (N = 14) compared to males (N = 5). Most of the group had secondary school and above educational level (76.9%) and were mostly living alone (70.0%). Almost half (48.5%) were employed. However, only 8.50% of individuals identified themselves as 'unemployed' at the time of the survey, while 43.1% were classed as 'economically inactive'. Of those screening positive for BD, 59.2% (77 / 130) reported receiving care for mental or emotional problems in the last year. Table 1 shows a summary of wider service use in individuals screening positive for BD.

Insert Table 1 about here

Our analyses show that, of 130 participants screening positive for BD, approximately 4 out of 10 did not receive any kind of mental or emotional healthcare in the community in the last 12 months. Approximately 15% had asked for specific help for their BD but had not received it. 60% of participants who screened positive for BD had spoken with their GP in the last 12 months; however, in the same period only 13.8% had seen a CPN, 13.1% a psychiatrist, and

4.60% a psychologist, while 16.9% had received treatment specifically targeting BD (medication and / or psychotherapy) in the preceding year. A small percentage (9.20%) had attended self-support groups.

3.2. Clinical factors and psychopathology

Table 2 shows the sociodemographic and clinical factors stratified by whether the individual received care in the last year. Figure 1 and 2 provides a graphical representation of these sociodemographic and clinical factors, respectively. Of those screening positive for BD and with data available, 38.5% had experienced persecutory delusions, 10.8% had auditory-verbal hallucinations in the last year, and nearly 30% had screened positive for borderline personality disorder. Approximately 31% reported having had suicidal thoughts in the previous 12 months and around 21% had suffered a depressive episode in the last 2 weeks.

Insert Table 2 about here

Individuals who were female, older (except the age band of 65 – 74), less educated, not in employment and living alone had higher frequencies of receiving mental health care. Those who reported having a comorbidity with borderline personality disorder and diagnosed with a previous depressive episode than those had a higher frequency of receiving care than those without such comorbidities. Individuals who positively endorsed questions on persecutory delusions, auditory-verbal hallucinations and suicidal ideation also had much higher frequencies of receiving care than those who did not.

Insert Figure 1 about here

Insert Figure 2 about here

3.3. Factors linked to accessing care

Weighted logistic regression analyses revealed that receiving care in the last 12 months was independently and significantly associated with female sex (p<0.0001, odds ratio (OR):4.65,

Confidence Interval (CI):2.18-10.30) and not being in employment (p=0.02, OR: 2.65, CI: 1.23-5.88). Suicidal ideation also significantly increased the odds (p=0.04, OR: 3.36, CI: 1.04-10.89) of being in receipt of care. Persecutory delusions, auditory-verbal hallucinations, presence of SCID-II borderline personality disorder, and having had a previous depressive episode did not show an independent association to being in receipt of care in the adjusted analyses (see Table 3 for details).

Insert Table 3 about here

4. Discussion

Prior to the APMS 2014, there had been no estimations of the lifetime prevalence of BD in the English general population. We found 1.72% of adults living in England screened positive for BD. Whilst the screen was not followed by clinical diagnostic assessment, this value is consistent with population estimates elsewhere of between 1.6% and 2.4% (Akiskal et al., 2000; Merikangas et al., 2011) that did use clinical diagnostic assessments. However, the latest Global Burden of Disease Study revealed a lowered prevalence of approximately 0.8% which did use diagnostic instruments to confirm cases (Ferrari et al., 2016). It is also very interesting that 29 individuals did not screen positive for BD even though they did report a BD diagnosis by a healthcare professional. We cannot comment on how far this single question was a valid measure of a diagnosis of bipolar disorder.

Of respondents screening positive in our sample, around 40% had not accessed any form of mental health care or spoken to any healthcare professional about their mental health in the last 12 months, while only 16.9% had had BD specific treatment in the previous year. The precise definition of BD specific treatment was not provided in the dataset. We anticipate respondents would have understood this to mean mood stabilisers and psychological treatment for BD, although we cannot be sure. Around 15% had sought specific treatment for their BD over the last year but were refused. It is possible that this group might not have been asking for the kind of care deemed most appropriate for the clinical situation or that the means to address their needs were not available. Certainly, possible remission in mood

stability or presence of mania in the past 12 months could have influenced being in receipt of care.

The estimation by the UK's National Institute for Clinical Excellence (NICE) in their most recent guidance (NICE, 2015) states that around 1 in 4 of adults with BD never sought help or treatment in their lifetime. Although a direct comparison cannot be drawn, the rate of individuals who did not seek care in the current study in the last 12 months is still very concerning, especially given that factors usually dealt with by GPs such as physical health illnesses and their monitoring can greatly impact the patients' lifespan (Young & Grunze, 2013).

4.1. Sociodemographic factors associated with receiving care

Age was not significantly linked to receiving care, despite the fact that current BD is more prevalent in younger people as shown in the latest APMS report (Marwaha et al, 2016). Our findings did not support previous research suggesting age is a factor (younger people having more difficulty) in accessing care as indicated by the long delay between symptom appearance, diagnosis and treatment in bipolar disorder (Berk et al., 2006). However, young people (aged 16 – 24) did demonstrate a lower frequency of receiving mental health care (approximately 42%) compared to individuals in their 30s or 40s, where over 65% had accessed care. This is consistent with previous literature (see Kozloff et al., 2010) and may indicate differences in symptom recognition, acceptance of their importance or accessibility and suitability of current services across the age groups. On the other hand, female respondents were significantly more likely to receive care. This may be related to previous findings that females are more comfortable with, and potentially better at, expressing their emotions and communicating needs for intervention (Judd et al., 2008; Oliver et al., 2005). Alternatively, it may reflect a bias in service responses to bipolar disorder symptoms, where clinicians are more likely to consider bipolar disorder in females (or less likely to in males), and to consider them as necessitating intervention. This was evidenced by a higher number of professional diagnosis of BD in females than in males in the current dataset. Not being in employment (including being economically inactive, such as early retirement) was also significantly linked to receiving care, probably through association with more severe symptoms and functional impairment.

11

4.2.   Clinical factors associated with receiving care

Levels of persecutory delusions, auditory-verbal hallucinatory experiences, borderline personality disorder, depressive episodes and presence of suicidal ideation differed significantly between individuals who successfully sought care and those who did not. According to analyses of previous iterations of the Adult Psychiatric Morbidity Survey (Bebbington et al, 2006), the vast majority (82.4%) of people diagnosed with a psychotic disorder (e.g. schizophrenia, also associated with severe and chronic functional impairment) were in touch with healthcare services and receiving treatment. We found that people with probable BD received considerably less in the way of care than those with psychosis, and the nature and extent of BD specific treatment were limited and not precisely defined. This was surprising, given that BD causes levels of morbidity broadly similar to those caused by psychotic disorders. It may also be linked with depressive symptoms in BD being misdiagnosed as major depressive disorder rather than bipolar depression (Hughes et al., 2016). This is not only a risk in primary care, as a recent audit found that even at presentation to secondary mental health services few patients with a depressive illness were asked about a history of hypomania (Hamad, Chertri & Zakaria, 2019).

It is widely assumed that psychotic symptoms are a measure of bipolar disorder severity including associated cognitive difficulties and may therefore be linked to accessing care (Glahn et al., 2007; Selva et al., 2007). However, psychotic symptoms appeared to have no significant effect in this analysis. This could be due to the fact that only a limited range of psychotic symptoms were assessed in this study, however, these symptoms (persecutory delusions and auditory-verbal hallucinations) were indeed the strongest available indicators of 'true' psychotic symptoms in a general population sample. Borderline personality disorder and bipolar disorder are comorbid in 20-40% of cases (Paris et al., 2007; Zimmerman & Morgan, 2013), and the severity of borderline personality symptoms might make access to care more likely. However, there is also concern that people with borderline personality disorder may be rejected by services (Lohman et al., 2017; Weight & Kendal, 2013). Again, our analysis found no evidence for either hypothesis.

Although 60% of those screening positive with BD reported receiving care for mental or emotional problems in the past year, only 16.9% had specific treatments for BD (e.g. mood stabilisers). This may reflect a lack of services available for BD patients or a general lack of diagnostic specificity in treatments being offered; it was not the case that a high proportion of people with probable BD who might need formal mental health services were diverting to non-statutory services such as self-help groups.

In the current multivariate analyses, psychotic symptoms were not strongly associated with access to care in individuals screening positive for BD, perhaps due to their relatively low frequency in cases in the community. By contrast, suicidal ideation was associated with higher frequencies of receiving mental health care. This may indicate that that they had reached a more severely symptomatic state or even a crisis point before accessing care, and that suicidal thoughts may be acting as a 'gate-keeping' criterion for access to care by secondary mental health services.

Further research is needed to look into the way people with BD access and interact with secondary mental health services. An Australian study reported that people with BD felt there was a lack of awareness and understanding about the illness in the community, and this was one reason why there were delays in seeking medical treatment. People also struggled to obtain accurate diagnoses and optimal treatment, and the authors described the healthcare system responses as inadequate (Highet et al., 2004). There is no equivalent research relating to the English or more widely British healthcare system.

4.3. Limitations

The main issue with the present analysis is the low power to detect some of the potential differences between groups. Some of the subgroups (e.g. those who did not receive care amongst those aged 16-24 years and those with narrowly defined psychotic symptoms) had very small numbers (but not small enough to warrant a Fisher's exact test) which could have been problematic with multivariate logistic regression analyses.

Despite its clinical utility and good psychometric properties, the instrument used to screen for BD has limitations. In fact, as mentioned previously, some individuals who reported receiving a professional diagnosis of BD in the past year were *not* picked up by the MDQ screening. Such individuals were excluded from the sample and classed as not having BD when calculating the lifetime prevalence.

As a screening tool, the MDQ is less sensitive than some other measures (e.g. the Hypomania Checklist or HCL; (Meyer et al., 2014)) at identifying Bipolar II disorders. Both the MDQ and the HCL (32-item and 16-item versions) are self-report measures and could suffer from common limitations such as over- or under-endorsement due to the participants' own perceptions of their experiences as well as issues with social desirability especially as they ask about legal troubles and drug use, for example. The application of the MDQ in the general population is also limited by its low sensitivity of 0.28 (i.e. the proportion with the condition screening positive) and thus the prevalence that was apparent may be an underestimate of the true rate. Subsyndromal bipolar states, which are more characteristic of cyclothymia rather than Bipolar I or II, might not have been picked up by the current instrument and risk being missed out completely. Had these subsyndromal states been included, the combined prevalence of all BD-related and BD-like symptoms is likely to have been higher. On the other hand, the use of self-completed SCID-II for borderline personality symptoms may have inflated their prevalence by the respondents' reporting only 'one or more' symptoms.

The data are cross-sectional. Longitudinal studies are needed to examine individual trajectories of symptom development and functional impairment, as well as access to care. In addition, psychotic symptoms in the current analysis were restricted to persecutory delusions and auditory-verbal hallucinations ('voices'). Delusions of grandeur and reference were not assessed in the APMS, and this may in part why we did not find an independent association between psychotic symptoms and being in receipt of care. Future studies need to further delineate the subtypes of psychotic symptoms and their associations with BD in the community.

Finally, the variable 'use of medication for BD' was not defined in detail in the survey. As such, it was difficult to distinguish between medications aimed at treating mood instability,

psychotic symptoms or depressive symptoms alone without assuming that these medications were specific for BD (i.e. mood stabilisers and anti-manic medications) in a narrow sense.

5. Conclusion

Our findings provide new data on the lifetime prevalence of BD spectrum disorders in the general population of England and the factors associated with access to mental health care. The finding that 4 out of 10 individuals with probable BD had received no mental health care in the preceding 12 months is of concern. It is possible they did not require it, though this is unlikely to be the explanation for most cases. Alternatively, they may not have realised they were unwell or had a mental disorder, or simply could not access secondary mental health care. Of all clinical variables, suicidal ideation was the only variable that was statistically significantly associated with accessing care. This could indicate people with BD need to reach a 'crisis point' before accessing mental health care and is consistent with the lack of new investment, or actual disinvestment, in services for people with BD, as in the case of Lithium Clinics in the UK. Given the associated morbidity and mortality, the small proportion of people with BD receiving BD-specific treatment, and the finding that 1 in 7 of those requesting specific treatment had been refused, our findings would suggest less than optimal care for this group. The National Health Service in England needs to address these shortcomings in care by actively screening for BD symptoms at initial GP consultations, re-invest resources in BD clinics focusing on the effective use of lithium and related mood stabilisers, and engage in better service provision and early intervention for BD by assessing at-risk states such as subsyndromal manic symptoms (Vieta et al., 2018).

Conflict of interest

SM has received funding from Lundbeck, Sunovion and Janssen to attend educational events. Other authors declare no conflicts.

Data availability statement

Data from the APMS can be officially obtained from the UK's NHS Digital upon reasonable request.

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