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The Experiences and Risks of Living with Bipolar Disorder.

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This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate
in Clinical Psychology.

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May 2015

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List of Abbreviations

BD – Bipolar Disorder

SUD – Substance Use Disorder

CD – Conduct Disorder

ODD – Operational Defiant Disorder

ADHD – Attention Deficit Hyperactivity Disorder

PTSD – Post Traumatic Stress Disorder

IPA – Interpretative Phenomenological Analysis

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Acknowledgements

I would like to thank all of the participants who shared their experiences with me, and were so open and trusting in their accounts. It was a privilege to be able to hear them. I would like to thank my supervisors, Dr Eve Knight Dr Carolyn Gordon, Dr Adrian Neal and Dr Lesley Pearson for being so generous with their time and support. I would especially like to thank Dr Knight and Dr Gordon for being so accommodating and understanding of my circumstances during the write up period. I would also like to thank Dr Julia Cook for her very sensible and much appreciated advice.

I would like to give special thanks to my Mother Marilyn and my husband Graham whose continued support and encouragement has enabled me to get through this process. Last, but not least, I would like to thank my darling little boy Laurie, who has, in one form or another been by my side during this research, and has been my inspiration.

Declaration

This thesis is an original piece of my own work, conducted under the supervision of Dr Eve Knight and Dr Carolyn Gordon. It has not as an entirety, or any part of it, been submitted for any other degree or to any other institution.

Summary

This thesis is an exploration of some of the risks associated with Bipolar Disorder and the lived experiences of people with Bipolar Disorder. It begins with a systematic review of the risk factors associated with Substance Use Disorder in adolescents with Bipolar Disorder. Eleven research papers, consisting of seven separate research projects were included for review. Support for a number of risk factors being implicated as causing a higher risk for the development of substance use disorder were identified. The majority of these consisted of individual factors such as co morbid mental health issues and exposure to trauma. However, these findings must be considered within the context of the methodological limitations of the current research body. Implications with regards to clinical practice are discussed.

The second paper reports on an Interpretative Phenomenological Analysis exploring the experiences of mania in adults with Bipolar Disorder. Six participants were recruited to this study and interviewed using semi-structured interviews. Three super ordinate themes emerged from the data; 'if you could bottle it and sell it', 'the darker side of mania' and 'Loss - past, present and future'. Participant's accounts were characterised by recognition of the positive but unsustainable nature of their manic experiences. Participants reflected upon the aftermath of their manic experiences and what it meant to live now as a person who had had this experience. Finally, participants considered the losses they had encountered as a part of their manic experiences, and the existential questions they had been forced to ask about their identities. The clinical implications of the findings and future directions for research are discussed.

The final paper is a reflective account of the researcher's journey through the research process. Particular attention is given to the researcher's sense of transitioning from trainee to competent researcher.

Chapter 1 Literature Review

A systematic review of the risk factors associated with Substance Use Disorder in adolescents with Bipolar Disorder

In preparation for submission to the Journal of Affective Disorders (See Appendix A for author instructions for submission)

Overall word count (excluding tables, figures and references): 7878

1:1 Abstract

Aims: Adolescents with Bipolar Disorder are at high risk of developing a co morbid Substance Use Disorder. This systematic review was conducted to critically review which risk factors are associated with the development of substance use disorder.

Method: ASSIA, Medline (OVID), Pilots Database, PsyArticles, PsychINFO, Pubmed, Scopus, Web of Science, CINAHL and Embase were searched for articles. Reference and citation searches were also conducted. A total of 11 papers met inclusion criteria.

Results: A number of factors which related to the presence of behavioural and psychiatric disorders, experiences of trauma, suicide attempts and family structure were reported. Findings are mixed, and considered within the context of methodological limitations.

Conclusions: This review indicates that there are a number of risk factors which may increase the risk of developing substance use disorder in adolescents with bipolar disorder. However, there is an absence of longitudinal, large scale research affecting the overall conclusions that can be drawn about risk factors. Implications for clinicians and service provision are discussed.

Keywords: Bipolar Disorder, Substance Use Disorder, Adolescents, Paediatric Bipolar Disorder, Risk

1.2. Introduction

1.2.1. Bipolar Across the Lifespan

Bipolar Disorder (BD) is an affective disorder characterised by episodes of manic and depressive states (Maniscalco & Hamnin, 2008). While prevalence data for BD varies across countries, populations and the applicability of DSM criteria, it has been estimated that BD has a life time prevalence of 0.1 % to 3.8% in adulthood (Dell’Aglia, Basso, de Lima Argimon & Arteche, 2013). Bipolar Disorder is associated with high rates of impairment, with many adults with BD experiencing high levels of social and functional difficulties, especially when compared to other types of mental disorder (Scott et al. 2014, Carra et al. 2014).

For many years the focus of research in BD was in adults. Recently there has been acknowledgement that Bipolar Disorder is clinically expressed in both children and adolescents (Carlson & Mayer, 2006). The rate of diagnosis of BD in patients under 18 has increased rapidly in the past 20 years (Moreno et al, 2007). There are few studies which examine the prevalence of adolescent onset BD (Maniscalco & Hamnin, 2008). However the estimated prevalence of BD is thought to be between 1.1% and 3 % (Van Meter, Moreira & Youngstrom, 2011) which is similar to the prevalence rate seen in adulthood.

There is debate about how much the symptoms used to diagnose BD in adults are visible in children and adolescents with BD, and how the expression of BD may differ depending on developmental stage (Carlson & Mayer, 2006). Despite these debates, the majority of studies investigating the phenomenology of BD in children and adolescents have found that symptom expression is similar to that of adults (Gupta, Agarwal & Sitholey 2012; Demeter et al, 2003; Lewinsohn, Klein & Seeley, 1995) with older adolescents seeming to be the most similar to adult presentations (Masi et al. 2006) with an episodic course of illness while the very young (7 years and under) present with a chronic set of symptoms (Danielyan, Pathak, Kowatch,

Arszman, & Johns 2007). In general, those with early onset BD present a diagnostic challenge as it is sometimes difficult to determine symptoms from normal youth behaviour (Carlson & Mayer, 2006).

The diagnostic criteria for Bipolar Disorder are split into Bipolar I Disorder, Bipolar II Disorder and Cyclothymic Disorder by the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013). Bipolar I Disorder (BP I) is characterised by at least one life time occurrence of a manic episode. A person who is in a manic episode may have an abnormally elevated, expansive or irritable mood with abnormally increased energy or goal directed activity. This mania will have a marked impairment in functioning or necessitate hospitalization. Some people with BP I may also experience periods of major depression. Usual age of onset of the disorder is around 18 years. In children and adolescents the differentiation between mania and normal behaviour for the developmental period can be hard to define and so diagnosis is done on a case by case basis using the child's own behaviour as a baseline. Bipolar II Disorder (BP II) is characterised by at least one episode of major depression and at least one episode of hypomania. Hypomania has similar characteristics to mania, but hypo manic episodes are shorter, and do not cause as much impairment to day to day functioning. People with BP II are more likely to present to clinicians during a depressive episode and are less likely to find their hypomania problematic than people with BP I. Usual age of onset is early to mid twenties. In children and adolescents, BP II can be less episodic than in adults, and is often associated with prolonged periods of irritability (5th ed; DSM-5; American Psychiatric Association, 2013). Cyclothymic disorder involves episodes of hypo manic symptoms and depression which do not meet criteria for a major depressive disorder or hypomania. In adults this must have occurred for two years in order to obtain a diagnosis and for one year in children and adolescents. Usual

age of onset is late adolescence or early adulthood and may be a risk factor for the development of BP I or BP II.

The Diagnostic and Statistical Manual of Mental Disorders Version V (5th ed.; DSM-5; American Psychiatric Association, 2013) criteria for Bipolar Disorder are slightly different to those in the previous version of the manual (4th ed., text rev.; DSM-IV-TR; American Psychiatric Association, 2000). The diagnostic and statistical manual of mental disorders (4th ed., text rev., 2000) included a diagnostic category called Bipolar Disorder Not Otherwise Specified (BP NOS) which was applied to all people not meeting formal criteria for BD I or BD II (Angst 2013). Instead the DSM V now includes a diagnosis called ‘Other specified Bipolar and Related Disorders’ which defines more specific symptoms for sub threshold Bipolar conditions. In the DSM V, criteria for mania and hypomania have been revised to be more expansive and include changes in activity levels as well as mood symptoms.

The current guidelines in Britain for the treatment and management of Bipolar Disorder in adults (National Institute of Clinical Excellence, 2014 (NICE)) recommend the use of medication for the management of manic symptoms, and appropriate psychological intervention for depressive episodes. NICE also recommends the use of psychosocial interventions that are Bipolar specific. The success of the type of intervention seems to be dependent on the current symptoms the person is experiencing. Miklowitz (2008) found that interventions focusing on treatment adherence and early warning signs were helpful for reducing mania, and interventions which focused on cognitive and interpersonal coping strategies were more helpful for depression.

The NICE guidelines also make recommendations for adolescent and childhood onset Bipolar Disorder. These are similar to those in adults, but also stress how important it is to have the family of the child involved as well as a multidisciplinary team. However, NICE also

highlights the lack of research into child and adolescent Bipolar Disorder, which makes the recommendation of treatment and management strategies difficult. As part of their research recommendations NICE emphasises the need for more research into child and adolescent Bipolar Disorder, specifically on psychological interventions which target the complexities of the disorder in these age groups.

As mentioned previously, BD in adulthood is associated with higher illness burden and poorer outcomes and prognoses than other mental health issues (Fajutrao, Locklear, Priaux & Heyes 2009). Early age of onset has been associated with a worse prognosis including higher rates of suicidal ideation and attempts, rapid cycling of mood states and are more likely to develop substance use disorder (SUD) (Carter, Mundo, Parikh & Kennedy, 2003). BD in children and adolescents also has a high level of persistence into later adolescence and adulthood. Wozniak et al (2011) found in a longitudinal study of children diagnosed with BD, that 93.6 % of those were still symptomatic at four year follow up and had experienced longer illness episodes than those whose symptoms were in remission. Perlis et al (2004) similarly found, in a retrospective study of 983 adults with BD, that 65.3% of these participants had experienced the first symptoms of BD when they were aged 18 years or under. The early onset BD adults were more likely to experience rapid cycling, co morbid disorder and suicide attempts than their adult onset counterparts.

People with BD experience a number of losses and burdens as a result of having BD. People who have early onset BD experience a similar set of symptoms to those with adult onset BD, however they face an even worse prognosis than their adult onset counterparts making them a particularly high risk and vulnerable group. One of the biggest issues associated with having BD is the high number of co morbid disorders.

1.2.2. Bipolar and Co morbidities

Both Adult and Early Onset BD are associated with a number of co morbid disorders. Adults with BD have been shown to have a higher rate of serious physical illness and mortality from those illnesses than controls (Schoepf and Heun, 2014). There have been similar findings in children and adolescents with BD. Jerrell, McIntyre & Tripathi (2010) found that children under 18 with BD were significantly more likely to have 2 or more chronic health conditions, including obesity, diabetes and cardio vascular disorders, than control participants. BD also seemed to lead to a more complex treatment burden in this sample as BD participants used more outpatient services and took longer to treat these disorders than controls with a similar diagnostic profile.

In a systematic review of recent research findings, Frias, Palma and Fariols (2015) found common co-morbidities of BD in early onset BD to be ADHD, Disruptive behaviour disorders, Anxiety disorders and Substance Use Disorders. Follow up studies have indicated a much worse prognosis in those without co morbid disorders (Birmaher et al. 2009).

1.2.3. Substance Use Disorders

One of the most common co morbidities of BD in adults is SUD (Grant et al. 2005).

Prevalence rates vary in adults but research has indicated up to 40% of all adults diagnosed with BD will experience co morbid SUD (Cerullo & Strakowski, 2007). The clinical impact of having a co morbid substance use disorder has been well documented for adults. A co morbid substance use disorder in BD adults has been shown to be a risk factor for suicide (Carrà, Bartoli, Crocamo, Brady & Clerici, 2014), lower life expectancy (Fenn et al. 2005), poorer remission rates of BD (Goldberg, Garno, Leon, Kocsis & Portera 1999) and poor treatment adherence and dropout (Sajatovic et al. 2008).

There has also been research which has suggested adolescents with BD are at higher risk of developing SUD than their non BD counterparts.

1.2.4. Prevalence rates

While a younger age of onset of BD has been shown to have a poorer prognosis when comparing under 18 to over 18 as a whole (Post et al. 2010), research into SUD in early onset BD has tended to focus only on adolescent subjects. This is in part due to the very small number of pre adolescent patients with BD and SUD who have been identified. Research has also suggested that people who develop BD as adolescents are more likely or more at risk of developing SUD than those who develop BD during childhood (Wilens et al. 1999).

Adolescents also have more access to substances than children and experience more peer related incentive to experiment with substances.

Adolescents with BD are at high risk of both using substances and developing SUD, due to their diagnosis and age group. While the physical and mental costs of using substances during adolescence are problematic, the development of SUD during early onset BD can have a devastating effect on the course of the BD illness. This makes adolescents with early onset BD who go onto develop SUD particularly important to focus research efforts on, in order to identify those at high risk and when and how to intervene.

1.2.5. Primary and secondary SUD

There have been several hypothesis suggested as to why BD and SUD have such strong associations (Tohen, Greenfield, Weiss, Zarate & Vagge, L. M. 1998). One hypothesis suggests that for some people, the presence of BD increases the risk of SUD, while others may only develop BD if they have had a SUD for a number of years.

Strakowski and Delbello (2000) noted that in a sample of 77 adult patients with first episode mania, 60% of them had developed an SUD prior to the onset of their BD symptoms, referred to as Primary SUD. Kenneson, Funderburk & Maisto (2013) found the opposite pattern with

most of the participants developing symptoms of BD well before they developed SUD, referred to as Secondary SUD. In adolescent samples there are some indications that this is a similar pattern, with some participants developing SUD prior to the onset of BD, and others developing BD initially and then SUD (Dell’Aglia et al. 2013) . This pattern has led to the suggestion that there are different sub groups of BD which has different interactions with SUD.

In adolescent samples, while there have been suggestions of both types of symptom course, the majority appear to be secondary SUD developing after BD (Kenneson et al. 2013). Those with primary SUD tend to be older at age of BD onset, for example Wilens et al (1999) found an average age difference of 5 years between the age of onset of BD in young adults with and without SUD. This suggests that there is a subgroup of adolescent BD who go on to develop secondary SUD. This group is particularly vulnerable and requires early targeted intervention in order to have the best chance of recovery.

1.2.6. Aim and Scope of the Current Review

The goal of this literature review was to systematically evaluate the research on risk factors associated with SUD in adolescents with Bipolar Disorder.

The recognition of Bipolar Disorder as a diagnostic category which is relevant to adolescents is in its infancy so it was anticipated that there would be a variety of published research on this topic, both in style and quality. Therefore a systematic review was considered the most appropriate approach to achieve the goal above as this method allows for a broad encompassing approach to data gathering (Centre for Reviews and Dissemination, 2009).

It was anticipated that this review would highlight the risk factors associated with SUD in BD, with a view to identifying those most at risk from developing SUD, and important areas for targeted early intervention.

1.3. Method

1.3.1 Search Strategy

Search terms were informed by the question “What are the risk factors associated with Substance Use Disorders in adolescents with Bipolar Disorder?”. Several different search terms were identified from published research in the field and synonyms were selected for different components of the question (Table 1).

Table 1.1.

Search terms based on the review question “What are the risk factors associated with Substance Use Disorder in adolescents with Bipolar Disorder?”

Concept	Bipolar	Substance Use Disorder	Adolescent
Search Terms	Bipolar	Substance Use Disorder	Adolescent
Additional Variations	Bipolar*, Mania, Juvenile Bipolar*, Paediatric/Pediatric Bipolar*	Substance*, Co morbidity, Dual Diagnosis	Adolescen*, Juvenile, Youth, Young People, Teen*

Note Terms taken from concepts 1,2 and 3 were combined using the Boolean operator “and”. * represents truncation to capture variation in the terminology. See appendix B for search term combinations used.

1.3.2. Data Sources

Initially both the Cochrane Database of Systematic Reviews and the Centre for Reviews and Dissemination (DARE) were searched to ensure that this review was an original contribution to the literature regarding BD and SUD.

Identified search terms were entered into ASSIA, Medline (OVID), Pilots Database,

PsyArticles, PsychINFO, Pubmed, Scopus, Web of Science, CINAHL and Embase on the 5th

March 2015. These databases were chosen to provide access to journals where content reflected the psychological and psychiatric nature of the review. To maintain consistency of searches, each database was searched by title only. See appendix for the results of each database search.

1.3.3. Selection Criteria

To assess articles retrieved through database searches for eligibility, inclusion and exclusion criteria were applied.

1.3.3.1. Inclusion Criteria

Studies were included if they: (i) had been published in a peer reviewed journal (to ensure quality of the research), (ii) included participants diagnosed with adolescent onset Bipolar Disorder and were evaluated for a SUD, (iii) measured and reported hypothesised risk factors for SUD present in the participant sample (iv) were published from 1980 onwards and included a diagnosis of BP which mapped on to ICD 10 (WHO, 1979, 10; 1992) or DSM (III, APA, 1980; III-R, 1987; IV, 1994; IV-TR,2000).

1.3.3.2. Exclusion Criteria

Studies were excluded if; (i) the paper was a review, commentary, book chapter, letter, conference proceeding, discussion piece or a legal paper, (ii) Bipolar Disorder was not the primary diagnosis, (iii) age of Bipolar Disorder onset was childhood (below 10 years) or adult (18 years and over), (iv) SUD preceded Bipolar Disorder onset, (v) substance use rather than substance abuse disorder was being examined (vi) the paper was not available in English, (vii) the study utilised a case study design.

1.3.4. Systematic Search Results – Study Selection

1.3.4.1. Phase 1

Initially, 870 articles were retrieved through the database search after limits were applied. These were saved to the Refworks interface and after duplicate removal, a total of 286 articles remained. Titles and abstracts were screened against the inclusion and exclusion criteria to produce 28 potential articles. Full-text versions of these articles were screened and 11 articles met the selection criteria.

1.3.4.2. Phase 2

The references of the 11 articles were hand-searched and scanned. This process revealed a further 14 potentially relevant articles. Scanning full-text articles revealed that none of these articles were suitable for inclusion. The total number of articles suitable for inclusion was 11. The study selection process is detailed in Figure 1, in accordance with PRISMA group guidance (Moher, Liberati, Tetzlaff & Altman, 2009).

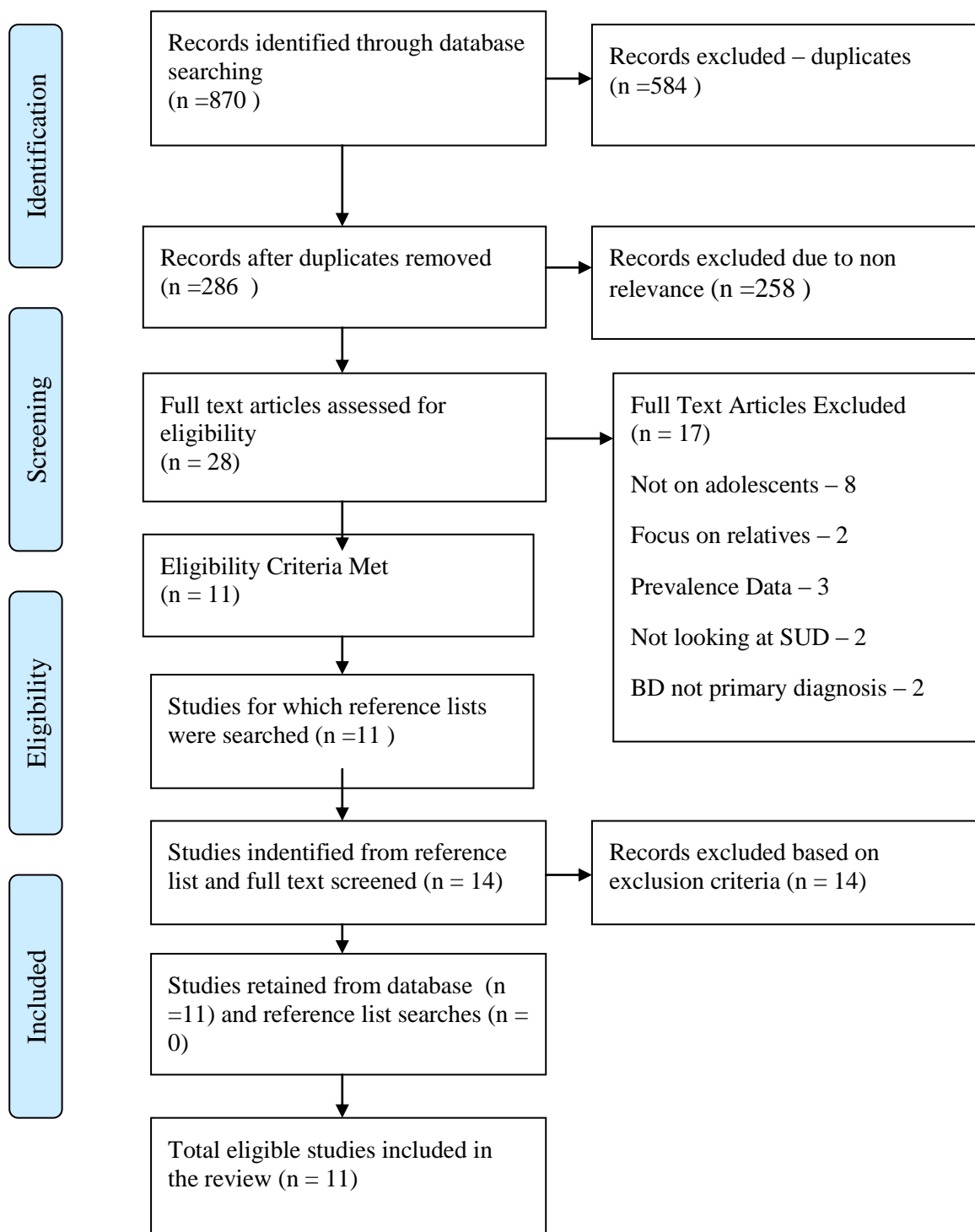


Figure 1. Systematic Search Strategy

1.3.5. Data Extraction and Synthesis

Following the identification of studies, a data extraction form was created for the review to ensure relevant information was consistently obtained and to enable the review of predominant themes for synthesis (Appendix C). This form was based on the Population, phenomenon of Interest/Intervention, Context, Outcome, Study Design framework (PICOS) (Joanna Briggs Institute, 2011).

1.3.6. Study Quality Assessment

Prior to examining the results of the identified studies, methodological quality was assessed to identify sources of bias in the review (Eiser, Hill & Vance, 2000). Studies were not excluded on the basis of receiving a poor quality rating, rather the quality assessment was used as a basis for examining quality of evidence when synthesising findings.

1.3.6.1. Quality Assessment Tool

The studies identified during the systematic review process all used similar study designs and aims, which focused on looking at associations or correlations. The National Institute for Health and Social Care Excellence (NICE) identifies that the main sources of bias in these types of studies are confounding factors from selection, and bias introduced through recall of participants in retrospective studies or withdrawal from prospective studies.

NICE has developed a quality checklist for these types of studies based on the 'Graphical Appraisal Tool for Epidemiological Studies' (Jackson et al. 2006) and focuses on the study's internal and external validity as a way of evaluating the amount of bias which may be in the study. As this quality tool was designed for the type of studies found by the systematic literature search it was decided to use this tool to evaluate the included studies.

1.3.6.2. Methods for Assessing Quality

Some of the questions in the NICE Quality Appraisal Checklist – Quantitative studies reporting correlations and associations (2012) were not appropriate as they were for evaluating studies where an intervention had been used. These were removed leaving 16 questions which focused on the minimisation of bias in the areas of population, selection of comparison, outcomes, analysis and general overview (see appendix D).

Each criterion was rated as either ‘yes’, ‘no’ or ‘partially’. ‘Yes’ was scored at two points, ‘partially’ one point, ‘no’ zero points. The total number of ratings was then calculated (out of 32) and a score provided which was then converted to a percentage (see appendix E). The mean quality percentage was 77% with a range from 75% to 78%.

1.4. Results

1.4.1. Findings Overview

The systematic search strategy detailed above results in 11 research papers meeting the inclusion criteria for review. These studies all examine adolescents with Bipolar Disorder who have co morbid substance use disorder. See table 1.2 for details of these studies. Due to the focus on the associated factors for SUD in adolescents with BD, only those factors are discussed in detail. The quality assessment enabled identification of a number of methodological limitations which are discussed later in this section. Some of the studies had an initial participant pool which included participants who were younger than 10 and older than 18. These studies were deemed appropriate to be included in the review as those participants fewer than 10 years of age did not display SUD and so were excluded from further analysis. Participants in the studies who were 18 years or above had been diagnosed

with Bipolar Disorder before the age of 18 so the studies were deemed appropriate to remain in the review.

All of the studies utilised quantitative methodology. Five out of the 11 used a prospective cohort design, five used a case control design and one used a retrospective cohort design. Six of the studies were based on data regarding different variables drawn from the same population. A further two studies were based on the same study population, but one was a longitudinal design while the other utilised a case control design. Ten of the studies examined the data drawn from American participants, one was on Italian participants. Findings, including critical analysis of the evaluations, are discussed below, beginning with individual risk factors and moving onto other types of risk factors.

Table 1:2

Description of reviewed studies

Reference	Quality Check Result	Country of Origin	Objective	Study Design	Population	Control	Measures	Statistics	Main Findings
Goldstein BI, Strober M, Axelson D, Goldstein TR, Gill MK, Hower H, et al. (2013). Predictors of first-onset substance use disorders during the prospective course of bipolar spectrum disorders in adolescents. <i>Journal of the American Academy of Child & Adolescent Psychiatry</i>, 52(10), 1026-1037.	78%	America	To examine factors that can help identify adolescents with Bipolar Disorder who are at particular increased risk of developing SUD.	Prospective Cohort Study	167 subjects, aged between 7 years and 17 years 11 months, who did not have SUD at intake and had at least one follow up interview drawn from the COBY study sample. Bipolar diagnosis included BP1, BP11 or BP NOS.	NA	K-SADS-PL, K-MRS, depression sections of K-SADS-P, LIFE, C-GAS, CBQ, FACES-II, LEC Family History Screen. Interviews with adolescents and parents.	Exploratory univariate survival analysis and multivariate regression analysis.	Variables significantly (p . 0.5) associated with increased risk of SUD were life time alcohol use, panic disorder, ODD, family history of SUD, low family history of cohesiveness and absence of treatment with antidepressants. There was a cumulative affect of risk factors, with the risk of SUD significantly greater when participants had three or more risk factors than participants who had less

									than three.
Goldstein BI, Strober MA, Birmaher B, Axelson DA, Esposito-Smythers C, Goldstein TR, et al. (2008). Substance use disorders among adolescents with bipolar spectrum disorders. <i>Bipolar Disorders</i> , 10(4), 469-478.	75%	America	To document the prevalence of SUD in the sample and to identify clinical and demographic factors associate with SUD.	Case Control Study	249 subjects (110 male, 139 female) aged between 12-17 years drawn from the COBY study sample. Bipolar diagnosis included BP1, BP11 or BP NOS.	NA	K-SADS-PL, K-SADS-DRS, K-SADS-MRS, SCID, Family History Screen, Life Events Checklist,. Interviews with adolescents and parents.	Exploratory univariate analysis and multivariate analysis.	Factors significantly associated (p < 0.5) with SUD were living with less than two biological parents and a history of physical and sexual abuse, being in trouble with the police and pregnancy and abortion in females. Significant (p , 0.5) predictors of SUD were conduct disorder and suicide attempt history.
Hua LL, Wilens TE, Martelon M, Wong P, Wozniak J, & Biederman J. (2011). Psychosocial functioning, familiarity, and psychiatric comorbidity in	82%	America	To examine the impact of psychotic symptoms in juveniles with BPD.	Prospective Cohort Study	N = 226 participants aged between 4 – 18 years. 151 with BD, and 75 with BD and	NA	KSADS-E, SCID, GAF, SAICA, FES, Vocabulary and Block Design subtests of	Logistic Regression	There was no finding that SUD was greater in the children with BD and psychosis.

bipolar youth with and without psychotic features. <i>Journal of Clinical Psychiatry</i> , 72(3), 397-405.					psychosis.		the Weschler Intelligence Tests		
Kenneson A, Funderburk JS, & Maisto SA. (2013). Risk factors for secondary substance use disorders in people with childhood and adolescent-onset bipolar disorder: Opportunities for prevention. <i>Comprehensive Psychiatry</i> , 54(5), 439-446.	78%	America	To determine the prevalence of potential risk factors for secondary SUD in people with childhood or adolescent-onset primary BD and to identify the factors that increase the chances of developing a secondary SUD in this population.	Retrospective cohort study.	N = 99 participants who developed BP aged between 13 and 18 years drawn from a larger sample from the NCS-R study cohort. There was also a comparison group of 59 participants who developed BD aged under 13 years.		CIDI,	Logistic regression, Proportional Hazards Model,	Significant (p < 0.5) predictors of SUD where being male, ODD, the presence of an anxiety disorder and a history of suicide attempts.
Lorberg B, Wilens TE, Martelon M,	75%	America	To compare the	Case Control Study	N = 105 adolescents	N = 98 non mood	KSADS-E, SCID,	Logistic Regression	The BD group were

Wong P, & Parcell T. (2010). Reasons for substance use among adolescents with bipolar disorder. <i>American Journal on Addictions</i>, 19(6), 474-480.			frequency, motivation and drug of choice for reported self medication by substance using adolescents with BD as compared to non mood disordered substance using controls.		aged between 10 – 18 years.	disordered controls aged between 10 – 18 years.	DUSI,		significantly more likely to use drugs to attenuate their mood than substance using controls (p=0.02).
Masi G, Milone A, Manfredi A, Pari C, Paziente A, & Millepiedi S. (2008). Comorbidity of conduct disorder and bipolar disorder in clinically referred children and adolescents. <i>Journal of Child & Adolescent Psychopharmacology</i>, 18(3), 271-279.	78%	Italy	To explore the clinical meaning of the CD-BD co morbidity in a large consecutive sample of referred children and adolescents followed up in a third level research hospital.	Case Control Study	N = 109 BD adolescents, N = 106 CD adolescents, N = 92 CD + BD adolescents		KSADS-PL, MOAS, CGI-S, C-GAS,	Last Observation Carried Forwards Analyses	Adolescents with both BD and CD were significantly more likely to have SUD than either CD or BD only adolescents (p=0.003).
Steinbuechel PH, Wilens TE, Adamson JJ, & Sgambati S. (2009). Posttraumatic	75%	America	To examine the relationship between BP,	Prospective Cohort Study	N = 105 adolescents aged between 10	N = 98 non mood disordered controls	KSADS-E, SCID,	Logistic Regression	Significantly more adolescents with BP had

stress disorder and substance use disorder in adolescent bipolar disorder. <i>Bipolar Disorders</i> , 11(2), 198-204.			SUD and PTSD.		– 18 years.	aged between 10 – 18 years.			PTSD than controls (p=0.003). Trends indicated a higher rate of PTSD in the BP adolescents with SUD than without.
Stephens, J. R., Heffner, J. L., Adler, C. M., Blom, T. J., Anthenelli, R. M., Fleck, D. E., et al. (2014). Risk and protective factors associated with substance use disorders in adolescents with first-episode mania. <i>Journal of the American Academy of Child and Adolescent Psychiatry</i>, 53(7), 771-779.	82%	America	To examine the clinical and demographic characteristics associated with SUD in adolescents with BD and to identify potential risk and resilience factors associated with the onset of a SUD after hospitalization for a first manic episode.	Prospective Cohort Study	N = 103 subjects, aged between 12 and 20 years, who were diagnosed with BPI and hospitalizes for the first time for a mixed or manic episode.	NA	WASH-U-KSADS, SCID-I/P, ASI,	Proportional Hazards Model	Factors significantly associated (p < 0.5) with a lifetime diagnosis of SUD were the presence of psychosis and physical or sexual abuse. Participants who developed SUD during the follow up period were significantly (p < 0.5) more likely to be older, have psychosis, PTSD and experience a

									manic rather than mixed episode at baseline than those participants who did not develop SUD.
									Treatment with stimulants prior to the development of BDI was a protective factor for SUD.
Wilens TE, Martelon M, Anderson JP, Shelley-Abrahamson R, & Biederman J. (2013). Difficulties in emotional regulation and substance use disorders: A controlled family study of bipolar adolescents. <i>Drug & Alcohol Dependence</i>, 132(1-2), 114-121.	75%	America	To examine DEST in a high risk sample of BD youth, non-mood disordered controls and their siblings.	Case Control Study	N = 74 adolescents aged between 10 – 18 years.	N = 139 adolescents aged between 10 – 18 years.	KSADS-E, SCID, CBCL	ANOVA, Logistic Regression	Both BD and non BD youth with high rates of DESR were at an elevated risk for SUD as compared to non elevated DESR youths.
Wilens TE, Martelon M, Kruesi MJ, Parcell T,	75%		To evaluate the associations	Case Control Study	N = 105 adolescents aged	N = 98 non mood disordered	KSADS-E, SCID,	Proportional Hazards Model,	Co morbid Conduct Disorder was

Westerberg D, Schillinger M, et al. (2009). Does conduct disorder mediate the development of substance use disorders in adolescents with bipolar disorder? A case-control family study. <i>Journal of Clinical Psychiatry</i>, 70(2), 259-265.			between BPD and SUD attending to the co morbidity with CD.		between 10 – 18 years.	controls aged between 10 – 18 years.	Linear and Logistic Regression Models,	not a risk factor for developing SUD in youths with BP, however it was associated with more complicated SUD and poorer overall functioning.
Wilens, T. E., Yule, A., Martelon, M., Zulauf, C., & Faraone, S. V. (2014). Parental history of substance use disorders (SUD) and SUD in offspring: A controlled family study of bipolar disorder. <i>American Journal on Addictions</i>, 23(5), 440-446.	75%	America	To examine the impact of parental SUD history on a combined sample of adolescents with and without BPD.	Case Control Study	N = 84 adolescents aged between 10 – 18 years. 65 with a parental history of SUD, 25 without.	N = 122 non mood disordered controls, aged between 10 – 18.	KSADS-E, SCID, Logistic Regression	Parental SUD significantly increased the risk of offspring SUD, this was not increased by the presence of BD in the offspring.

1.4.2. Key Findings

1.4.3. Individual Risk Factors

There were a wide variety of individual risk factors examined by the studies included in this review. In order to enhance clarity, each of these individual risk factors will be discussed.

1.4.3.1. Behavioural/Attention Disorders

1.4.3.1.1. Conduct Disorder

Four of the studies examined the role of co morbid conduct disorder in the development of SUD (Masi et al, 2008;Goldstein et al. 2008; Wilens et al, 2009; Kenneson et al 2013). Masi et al (2008) found that participants with a co morbid conduct disorder (CD) had higher rates of substance abuse disorders than participants with only conduct disorder or bipolar disorder. Goldstein et al (2008) found that rates of conduct disorder were significantly higher in the adolescents with SUD. Wilens et al (2009) found that the presence of CD was not associated with any additional risk of developing SUD in BD, however it was associated with a more complex SUD presentation and poorer overall functioning. Kenneson et al (2013) did not find that the presence of CD was significantly higher in adolescents with BD and SUD when compared to those with BD alone.

Although conduct disorder appears to be associated with BD and SUD in adolescents from the above evidence, there are several issues which make the relationship between the three disorders difficult to determine. In terms of the quality checklist, all of the research received a similar quality rating. However, Wilens et al (2009) was the only study to use a control group of non BD participants, which suggests

that conduct disorder may lead to a more complex presentation of SUD rather than be a risk factor for it. Kenneson et al (2013) and Goldstein et al (2008) did look at the temporal relationship between CD and SUD (which came first). Kenneson et al (2013) determined whether CD was present before the onset of SUD, and found no significant effect of this on the development of SUD. Goldstein et al (2008) also looked at the time of CD onset but only to the year of occurrence which makes it difficult to determine which came first and therefore which disorder, if either, had an influence on the development of SUD. These studies determined the onset or presence of a disorder by using diagnostic checklists. These checklists do not take into account when sub threshold symptoms may have begun which make it difficult to determine the relationship between the disorders and how that affects course. For example someone may have experienced the onset of both BD and CD sub threshold symptoms at the same time, but have reached clinical levels at different times. Those sub threshold symptoms may have had an equal influence on the person developing SUD, regardless of which disorder reached clinical levels first.

1.4.3.1.2. Operational Defiant Disorder

Two of the studies examined the role of co morbid Operational Defiant Disorder (ODD) in the development of SUD (Goldstein et al, 2013; Kenneson et al, 2013). In a prospective cohort study, Goldstein et al (2013) found that those participants who had been diagnosed with ODD at intake assessment were more likely to develop SUD during follow up than those who had not. Kenneson et al (2013) in a retrospective cohort study found adolescents with ODD were more likely to develop secondary SUD than those without. Both studies examined the risk of developing secondary SUD, indicating that an existing SUD did not cause the development of the ODD or BD, however Kenneson's et al (2013) study was based on an existing

data set not explicitly collected for this study which may affect the conclusions which can be drawn from this evidence. There was also no control group used in either study so a comparison to the rates of SUD in non BD ODD cannot be made. Both of the studies received the same quality rating.

1.4.3.1.3. Attention Deficit Hyperactivity Disorder (ADHD)

Four of the studies examined the role of ADHD in the development of SUD in BD (Goldstein et al 2008, 2013; Kenneson et al 2013; Stephens et al, 2014). A further study included ADHD as a variable but did not make sufficient comparisons to assess the relationship (Masi et al 2008). None of the studies found the presence of co morbid ADHD to be a significant predictor of the development of SUD.

1.4.3.2. *Co-Morbid Psychiatric Disorders*

1.4.3.2.1. Anxiety Disorders

Four of the studies evaluated the affect of co morbid anxiety disorders on the development of SUD. Goldstein et al (2013) found that the presence of a panic disorder was a significant risk factor for the development of SUD. Kenneson et al (2013) found that the presence of any anxiety disorder was a significant predictor of the development of SUD. However Goldstein et al (2008) and Stephens et al (2014) did not find significant associations with anxiety disorders and development of SUD. The sample of participants in both of Goldstein et al studies are the same, the 2008 study being based on baseline data while the 2013 is the follow up result. The discrepancy in findings could be due to anxiety disorders being a relevant predictor of SUD only in those participants who went on to develop SUD during the course of the research. In terms of the quality of the studies affecting how the results are

viewed, the overall methodological qualities of the studies was very similar and so do not suggest which findings to give more weight to on the basis of quality.

1.4.3.2.2. Psychosis

Three of the studies examined the effect of psychosis on the development of SUD (Goldstein et al 2008; Hua et al, 2011; Stephens et al, 2014). Goldstein et al (2008) and Hua et al (2011) found no difference between adolescents with BD and Psychosis and without in terms of their rates of SUD. Stephens et al (2014) in a longitudinal study found that in adolescents hospitalised for a first manic episode, those who went on to develop SUD during follow up were significantly more likely to have psychosis prior to the onset of their SUD. There were many methodological differences between these studies which may have caused the discrepancy in results. Stephens et al (2014) looked at BD I cases who had been hospitalised while Goldstein et al (2008) and Hua et al (2011) data was a baseline measurement drawn from a sample consisting of participants diagnosed with BD I, BD II and BD NOS. Stephens et al (2014) sample had an older mean age which has been noted as a risk for developing SUD. None of the studies used control/comparison groups so the independent affect of psychosis cannot be controlled for. In terms of quality, the Stephens et al (2014) study received a slightly higher rating due to the longitudinal nature of the study. Stephens et al study may have been better able to capture the changes which occur during a manic episode and have an effect on the development of SUD due to the design of the study.

1.4.3.2.3. First Episode Type (Bipolar Disorder)

One of the papers looked at the influence of the first episode on the development of SUD. In participants who were hospitalised for their first manic episode Stephens et

al (2014) found that, using a proportional hazards model, a manic first episode rather than a mixed presentation was a significant risk factor for the development of SUD. However, there was no control/comparison group in the study and sample size was small making it difficult to draw any solid conclusions.

1.4.3.3. Other Individual Factors

1.4.3.3.1. Experiences of Trauma

1.4.3.3.1.1. History of Sexual Abuse

Three of the studies looked at whether a history of sexual abuse was a risk factor for the development of SUD. Goldstein et al (2008) found that sexual abuse history was significantly higher in those with BD and SUD, however when this was entered into a logistic regression model for predictors of the development of SUD, sexual abuse history was not a significant predictor. This was replicated in the follow study by Goldstein et al in 2014. Stephens et al (2014) also found similar results. While life time diagnosis SUD in their sample was associated with a history of sexual abuse, it was not a significant predictor of the development of SUD. The association of sexual abuse and the development of SUD remains unclear from the above evidence. In studies where sexual abuse has been recorded as a variable, significantly higher numbers of those with SUD are noted, however this is not a robust predictor of the development of SUD, possibly because it has not been examined whether the sexual abuse occurred before or after the onset of SUD. Participants in these samples were in adolescence and their parents also completed some of the measures. It may be that this age group, who are vulnerable to both familial and stranger abuse, were unable to report the existence of this to interviewers. In terms of quality, all of the studies received similar ratings.

1.4.3.3.1.2. Post Traumatic Stress Disorder (PTSD)

Three of the studies examined the association between PTSD, BD and SUD (Goldstein et al 2008; Steinbuchel et al 2009; Stephens et al 2014). In all studies, a positive correlation between the three disorders was found. In Stephens et al (2014) the presence of co morbid PTSD was a significant predictor of the development of SUD in participants experiencing their first manic episode with a BD I diagnosis. Steinbuchel et al (2009) found only a trend of PTSD being present rather than a significant proportion in their baseline measurement of adolescents with BD and SUD. Secondly in their sample, only three out of the seven participants with BD, SUD and PTSD developed their SUD after the onset of PTSD. While Goldstein et al (2008) found that there was a significantly higher proportion of the participants with PTSD who developed SUD, when this was used as a predictor variable in further analysis, the relationship was no longer significant.

There appears to be higher rates of PTSD in adolescents with BD and SUD in the above evidence, however small sample sizes make determining the nuances of this relationship difficult. In terms of quality the studies had very similar ratings.

1.4.3.3.2. Emotional Regulation

One study looked at emotional regulation skills and the development of SUD. Wilens et al 2013 found that rates of poor emotional regulation were higher in the sample of adolescents with BD as compared to controls. However, poor emotional regulation did not prove to be an additive risk factor for SUD in adolescents with BD, rather both controls and those with BD who had poor emotional regulation were at risk of developing SUD. To be classed as having poor emotional regulations skills, participants had to score at least one standard deviation above the mean clinical

score on three sub scales of the child behaviour checklist. This may not have been a valid measure of emotional regulation.

1.4.3.3.3. Self Medication

One study examined the reason adolescents with BD and controls gave for taking substances, in an effort to determine if there were differences in why these two groups took substances (Lorberg et al, 2010). Adolescents with BD and SUD were more likely than controls to report that they took substances in order to alter their mood, in other words to self medicate. However, sample sizes were very small (27 BD vs 13 control) and so were not generalisable due to low experimental power.

1.4.3.3.4. Suicide Attempts

Three studies looked at the risk factor of suicide attempt in the development of SUD. Goldstein et al (2008) found that those with BD and SUD were significantly more likely to have a history of suicide attempt. Goldstein et al (2008) also found suicide attempt to be a significant predictor of the development of SUD, however this finding was not replicated in the 2014 follow up study of the same participant sample. Kenneson et al (2013) found that a history of suicide attempt was the biggest single predictor of co morbid SUD in their sample. None of these studies utilised control groups so it is difficult to determine the risk that suicide attempt confers on its own. Also, in the Goldstein et al 2008, the temporal aspects of suicide as compared to onset of BD were not ascertained. This makes it difficult to determine whether suicide attempt is a risk factor to developing SUD, a consequence of SUD or a combination of both. This may also explain the discrepancy in findings across the two Goldstein et al studies. In terms of quality, all the studies had very similar quality ratings.

1.4.4. Summary of Individual Risk Factors

Within the 11 studies identified by the search strategy a number of individual risk factors for the development of secondary substance use disorder in adolescents with Bipolar Disorder were identified. The presence of co morbid conduct disorder, oppositional defiant disorder, post traumatic stress disorder, a history of sexual abuse and suicide attempts all were found to increase the risk of developing secondary SUD. However, the evidence for each of the risk factors is low, with small sample sizes and lack of control groups making it very difficult to draw conclusions from the evidence base. All of the studies use correlation or association designs and while most of them are careful to look at risks which were present prior to the onset of SUD, correlation designs make it very difficult to determine the direction of causality.

1.4.5. Familial Risk Factors

There were a number of familial risk factors for substance use disorder in adolescents with BD identified by the studies. Familial risk factors are those that occur as a part of the participants' family history or family structure.

1.4.5.1. Family History of SUD

Three studies examined the role that a parental history of SUD would have on the development of SUD in adolescents with BD. The results from these studies are mixed. Two of the studies looked at longitudinal data. In a retrospective study of adolescents who developed SUD, Kenneson et al (2013) found that parental history was not predictive of SUD. However, in a prospective study of adolescents with SUD, Goldstein et al (2013) found that a family history of SUD was a significant

predictor of SUD. Neither of these studies utilised a control group but did have a similar participant population. Wilens et al (2014) did use a control group in their study and found that while the presence of a parent with a history of SUD increased the risk of developing an SUD in both the control and experimental group, this risk was not higher in the adolescent with BD group. As a parental history of SUD is an established predictor of SUD development in offspring these findings indicate that this is the case in those with BD also, but does not cause an inflated risk. In terms of quality, these studies had very similar ratings.

1.4.5.2. Family Cohesiveness

One of the studies examined the effect of family cohesiveness on the development of SUD. Goldstein et al (2013) found that participants who developed SUD in their sample, rated their family cohesiveness as lower than those who did not. This was a significant predictor of the development of SUD. However, no control group was used in the study and ratings were based only on the adolescent's view of the mother rather than both parents which make it difficult to base conclusions on this.

1.4.6. Summary of Familial Risk Factors

There were two familial risk factors identified in the reviewed studies as being associated with the development of SUD. Family history of SUD had the best quality evidence for being a risk for the development of SUD, but this was not thought to have a higher amount of risk for adolescents with BD than adolescents in the general population.

1.4.7. Additive Risk Factors

Seven of the identified studies looked at the effect of a single risk factor on the development of SUD. Four of the studies looked at a wider range of variables and used them to create predictive models using regression analysis. Regression models indicate how much a particular risk factor is likely to be present with the expected result i.e. a history of sexual abuse and the presence of SUD. Two of the papers looked at additive risk factors (Kenneson et al 2013; Goldstein et al 2013). Kenneson et al (2013) found that boys with none or one of the identified risk factors had 0% frequency of SUD, while boys with three risk factors had a 73.7% frequency of SUD. Boys who had all four of the identified risk factors had 100% frequency of SUD. Girls had a similar picture with the presence of one risk factor having a 10 % frequency of SUD, three risk factors a 62.5% frequency and all four risk factors a 100% frequency. This not only indicates that the more risk factors present indicate a higher risk of developing SUD but that the risk rapidly increases rather than proportionally increases. Similar results were found in Goldstein et al (2013) who found that, in their sample, 57% of those with three or more risk factors developed SUD compared to 14.1% of those with less than three. This again indicates a compound effect of the presence of risk factors.

1.4.8. Protective Factors

Although the studies identified in the search strategy were looking at risk factors for the development of SUD some protective factors were also identified during the analyses.

1.4.8.1. Family Structure

One study looked at family structure as a risk factor to the development of SUD.

Goldstein et al (2008) found that living with both biological parents was a significant negative predictor of developing SUD.

1.4.8.2. Use of Psychiatric Medication

Two of the studies found that the use of prescribed psychiatric medication had a protective effect on the development of SUD. Goldstein et al (2013) found in a prospective study of adolescents with BD, those who were prescribed lithium during treatment for mania were less likely to develop SUD during follow up. Goldstein et al (2013) also found that in the study described above, those who were taking antidepressants at baseline were less likely to have a co morbid SUD. Stephens et al (2014) found that treatment with stimulants prior to the onset of BD appeared to be a protective factor in the onset of SUD after BD was diagnosed. However, these studies did not look at the details of the prescribed medication i.e. what it was prescribed for, treatment adherence, optimal versus subclinical dose. This makes it particularly difficult to determine, what, if any, were the protective mechanisms of taking medication, or whether medication adherence points to another protective factor such as help seeking behaviour, better general medical care or longer in the mental health system.

1.5. Discussion

1.5.1. Summary and Discussion of Findings

The reviewed studies indicated that there were several risk factors associated with the development of SUD in adolescents with BD, that these risk factors could be

individual or external in nature and that there may be an additive effect of having one or more of these risk factors.

Overall, individual risk factors were the most assessed in the studies identified. A history of attempted suicide and overall co morbidity with other psychiatric disorders had the most robust evidence, however in all of the studies small sample sizes and/or lack of control groups meant any results should be interpreted with caution.

For the risk factors identified in more than one study there were variations and contradictions in the reported results. This could be attributed to variances in the aims of the studies, but they may also be attributable in part, to variances in, and limitations of the studies' methodology.

1.5.2. Consideration of Methodological Limitations

1.5.2.1. Study Design

All of the studies utilised a study design which looked at associations or correlations of certain variables with BD and SUD. While this type of design is very useful for identifying areas for further experimental study, they are unable to determine causality.

1.5.2.2. Sample Size

None of the studies used power analysis to inform them of requisite sample size needed to adequately detect effects. The studies had a sample size which ranged between 105 to 307 participants. These are fairly small sample sizes, especially when assessing the associations of multiple variables. When these sample groups were divided further into subsets such when comparing adolescents with BD, SUD and PTSD and those with BD and SUD only, group sizes became particularly small. In

the studies looking at number of variables (Goldstein et al 2008, 2013; Masi et al 2008; Kenneson et al 2013, Stephens et al 2014) using small sample sizes while making multiple comparisons which were not corrected for statistically there is an increased risk in a type II errors. Conversely for the studies looking at singular variables (Hua et al 2011; Lorborg et al, 2010; Steinbuchel et al 2009; Wilens et al 2009; Wilens et al 2013; Wilens et al, 2014) there is an increased risk of making a type I error.

1.5.2.3. Control Group

Five of the studies utilised a control group (Lorberg et al, 2010; Steinbuchel et al 2009; Wilens et al 2009; Wilens et al 2013; Wilens et al, 2014). A further study compared rates of SUD in BD to another clinical group (CD) but did not use a control group from the general population. While the sample sizes of both the experimental and control groups were small in the above study, this did mean that the effects of the variables examined could be separated from the effect of Bipolar Disorder. However, the control groups in the studies could not be randomly allocated to groups as it was the presence or absence of BD which determined which group they were put into. This may have made the groups less well matched, introducing the possibility of confounding variables.

For those studies that did not use a control group, it is even more difficult to make conclusions about which risk factors are associated with SUD in BD. While these studies compared differences between adolescents with BD and with or without SUD, the lack of normal controls or controls from another psychiatric population make it difficult to determine which are genuine risks for developing SUD.

1.5.3. Limitations of the Review

The literature review was conducted in a systematic way in order to critically evaluate the evidence for risk factors associated with SUD in adolescents with BD. However there exist some limitations which may affect the overall validity of the review.

Identified studies were limited to those published in the English language. This criterion may have resulted in the exclusion of potentially relevant research published in other languages. Additionally, all of the identified papers were from the United States, apart from the Masi et al (2008) which was conducted in Italy. This may mean the results of the review are not relevant to non western cultures. The identification of studies only from peer reviewed journals, while intending to ensure quality of retrieved studies may have resulted in publication bias, obscuring those with non significant results and potentially over estimating the association of risk factors with the development of SUD.

Due to the scarcity of research, a number of concessions were made; some of the studies used the same participant pool and therefore may have been over represented in the review. Furthermore, there were variations in the type of Bipolar Disorder endorsed by the diagnostic criteria used in the studies. While all of the studies used the same, well validated and highly reliable instrument in their screening and diagnostic procedure, there were different rates of Bipolar Disorder I, Bipolar Disorder II and Bipolar Disorder NOS included in each of the participant samples. It has been argued that different types of BD diagnosis represent not different subtypes of the disorder, but rather different disorders which have been grouped using the same descriptive criteria (Judd et al, 2003). However, in the studies where different

subtypes were compared, no significant differences were found, indicating type of BD may not have an influence.

The decision to exclude studies where sub threshold substance use is reported rather than SUD was a considered one, based on the serious prognosis this causes for adolescents with BD. However, substance use in general or substance dependence such as nicotine dependence and excessive alcohol abuse also has serious consequences for the adolescent engaging in them. It is possible that the risk factors for substance use are similar to those for substance use disorder, however in order to keep this review specific and manageable studies examining sub threshold substance use were excluded.

The quality checklist in this review has been recommended by NICE (2012) as a means of assessing the quality of the types of study design included in this review. However, as all of the papers received a similar rating using this tool it was not particularly discriminatory it was difficult to use this as a means of giving weight to the results. A checklist which included other variables as quality indicators may have been helpful.

1.5.4. Clinical Implications

Despite the methodological limitations of the studies presented in this review, there is evidence to suggest that there are a number of risk factors associated with the presence of SUD in adolescents with BD. Given the rising recognition of BD in adolescents and the recent guidance on how to more thoroughly assess and work with this group (NICE 2014) there are now ample opportunities for professionals to assist adolescents with BD and SUD before these problems become chronic.

The following are clinical recommendations drawn from the findings of this systematic review, for professionals who work with adolescents who have been diagnosed with Bipolar Disorder.

- Adolescents with Bipolar Disorder are at risk from developing Substance Use Disorder
- Professionals should try to identify substance use in order to prevent this developing into substance use disorder.
- Assessments should be aware of risks and ask questions related to substance use disorder as well as professionals being aware of the signs of substance use disorder while working with these adolescents
- Risk assessment procedures should take account of the presence or absence of risk factors associated with SUD in order to identify vulnerable groups
- The presence of three or more risk factors indicate a particularly at risk individual who may benefit from early targeted intervention.

1.5.5. Future Directions

The risk factors associated with BD and SUD may be a causative factor or a result of these two disorders. In order to determine more thoroughly this relationship, large scale, longitudinal studies with adequate control groups are required. The results of these would enable professionals to target health, psychological and psychiatric intervention in the areas most needed. This type of study would also help to answer the question of whether Bipolar Disorder alone was a risk factor for SUD, as some

researchers have posited or whether the relationships between these disorder was more complex than this.

1.6. Conclusion

Adolescents with Bipolar Disorder are at particularly high risk of developing co morbid substance use disorders. In relation to the aims of this review, a number of studies which have looked at potential associated risk factors for developing SUD in this group have been identified. Identified risk factors are both internal and external in nature, however, more long term and larger studies are needed to replicate these results before they can be judged to be risks specifically to those with BD rather than the general population. The implications for professionals working with this group have been considered.

1.7. References

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Chapter 2: Empirical Paper

The lived experience of mania in people with Bipolar Disorder.

Prepared for submission to Journal of Psychology and Psychotherapy: Theory,
Research and Practice (please refer to Appendix F for instructions for authors for
submission)

Overall chapter word count (exclusive of figures, tables and quotations):7693

Words in quotes and tables = 2272

2:1 Abstract

Aims: The lived experience of Bipolar Disorder has received little research attention. Mania, in particular, is little understood and is often seen as the opposite to depression rather than a complex experience. This study aimed to explore in detail the experiences of mania in people who had been diagnosed with Bipolar Disorder.

Method: Six participants were recruited to this study. Semi-structured interviews were conducted and analysed according to Interpretative Phenomenological Analysis (IPA).

Results: Three super ordinate themes emerged from the data; ‘if you could bottle it and sell it’, ‘the darker side of mania’ and ‘Loss- past, present and future’. Participant’s accounts were characterised by recognition of the positive but unsustainable nature of their manic experiences. Participants reflected upon the aftermath of their manic experiences and what it meant to live now as a person who had had this experience. Finally, participants considered the losses they had encountered as a part of their manic experiences, and the existential questions they had been forced to ask about their identities.

The clinical implications of the findings and future directions for research are discussed.

Keywords: Bipolar Disorder, Mania, Lived Experience, Interpretative Phenomenological Analysis, IPA

2.2. Introduction

2.2.1. Bipolar Disorder.

Bipolar Disorder refers to a condition which is characterised by episodes of mania and depression. Mania is defined as an excessive amount of mental and physical energy (Conos & McGorry, 2002). The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) further defines Bipolar Disorder by stating it falls into two categories, one which is characterised by episodes of mania (Bipolar I Disorder) which may involve delusions and hallucinations and another which is characterised by episodes of hypomania, a feeling of euphoria and high energy (Bipolar II Disorder).

However, in reality the experience of Bipolar Disorder is far more complex than these definitions would suggest, with each individual who is diagnosed as Bipolar Disorder experiencing very different combinations of symptoms and difficulties (British Psychological Society, 2010). The episodic nature of the disorder also contributes to the different experiences of those with Bipolar Disorder. Episodes of mania or depression can last for days, weeks or months, they can cycle or people may experience one episode and then not relapse for many years.

Bipolar Disorder prevalence rates are hard to determine due to diagnostic difficulties (Proudfoot et al., 2009) but current estimates suggest that 1-1.5 % of the UK and US population meet the criteria for the disorder (British Psychological Society, 2010).

2.2.2. The Lived Experience of Bipolar.

Bipolar Disorder has many negative consequences, due to the burden of episodes of mania and depression, as well as associated risky behaviours such as promiscuity and alcohol and drug abuse (McCandless & Sladen, 2003). Bipolar Disorder has a high rate of disability burden associated with it such as high mortality and suicide rates, high rates of substance use disorder, poor physical health prognosis and low rates of employment (McCrone et al. 2008). Bipolar Disorder has also been shown to have an adverse effect on memory, with mania causing memory loss (Elshahawi et al., 2011). However, many people who experience Bipolar Disorder symptoms also describe benefits of having Bipolar Disorder, such as heightened creativity (Lobban, Tyler, Murray and Jones, 2012).

Bipolar Disorder is often reported on and researched from a medical perspective and focuses on medication, negative symptoms, management techniques and enhancing treatment adherence (Lobban et al, 2012; Veseth et al 2012). While focusing on this perspective may enhance some of the methods currently used to treat Bipolar Disorder there is recognition that Bipolar Disorder has been poorly explored from the perspective of people living with it (Rusner, Carlsson, Brunt & Nyström, 2009). There are several reasons why examining the experiences of those with Bipolar Disorder is of benefit, to researchers, clinicians and of course, people with Bipolar Disorder.

As stated previously the diagnostic criteria for Bipolar Disorder is a simplistic representation of the combinations of symptoms that people diagnosed with Bipolar Disorder experience and so research into the lived experience of the disorder can highlight the rich variety of experiences which fit under the Bipolar Disorder banner

(Cross and Walsh, 2012). Experience research can also highlight what useful interventions may entail, what recovery is for people with Bipolar Disorder and how it can be promoted (Fernandez, Breen & Simpson 2014; Veseth et al, 2012; Michalak et al, 2006), ambivalence to medical models and treatment strategies (Lobban, Taylor, Murray & Jones 2012, Veseth et al, 2012) and the psychological impact of a disorder which has often been conceptualized as a chemical imbalance. Understanding lived experiences is important to close the gap between biological and pharmacological understandings of Bipolar Disorder and by doing so should make medical, pharmacological and psychological approaches to Bipolar Disorder more relevant to the person living with the disorder.

Existing research into the experiences of people with Bipolar Disorder has highlighted a number of important themes. In a review of accounts of Bipolar Disorder, Chouinard (2012) noted that the majority of clinical literature regarding Bipolar Disorder focused on its' biomedical aspects, such as effective drug treatments rather than other aspects of the experience such as what it is like to live with the disorder. This focus positions Bipolar Disorder as a problem or madness that needs to be removed, rather than accepting other ways in which Bipolar Disorder may be viewed by the individual, such as potentially positive aspects of the disorder.

Proudfoot et al. (2009) found in interviews with people newly diagnosed with Bipolar Disorder, there was a theme of ambivalence towards the diagnosis. This may have affected how well people were able to adhere to treatment recommendations. Other studies looking at narratives of recovery in people with Bipolar Disorder have similarly found themes of ambivalence towards the management of Bipolar Disorder (Mansell, Powell, Pedley, Thomas and Jones, 2010, Veseth et al, 2012).

Other researchers have focused on what it means to be a person with Bipolar Disorder, and how this may affect their quality of life. Rusner, Carlsson, Brunt and Nyström (2009) found living with Bipolar Disorder involved experiencing an extra intensity in all aspects of life. For instance, the participants described not just experiencing periods of mania and depression, but how having Bipolar Disorder infiltrated their whole lives, and participants were always trying to incorporate this into their understanding of the world and the self. Lobban, Taylor, Murry and Jones (2012) found that when people with Bipolar Disorder were encouraged to talk about the positive impact that Bipolar Disorder had on their lives, participants reported that this was something the medical establishment had not wanted to know from them. However, many of the participants stated that their experiences of Bipolar Disorder were intensely valuable to them and saw Bipolar Disorder as a gift that had enriched their lives. Research into the meaning of being a person with Bipolar Disorder has also described themes of stigma (Mickalak et al., 2011; Hawke, Parikh & Michalak 2013) and a loss of personal control and autonomy (Crowe et al 2012; Fernandez et al, 2014).

2.2.3. The Experience of Mania.

Although lived experience research has started to grow, there has been little research into the experience of mania as part of the Bipolar Disorder experience. Mania has often been associated with a heightened sense of confidence, self esteem and drive. However, research into self reported quality of life has suggested that people who are in a manic state do not have higher perceived quality of life than their peers who are in a depressed state, suggesting that assumptions about the function of mania being beneficial for individuals is not always reflective of their actual experience (Vojta, Kinoshian, Glick, Altsholer & Bauer, 2001). Specific themes regarding the experience

of mania have been identified in studies of the experience of Bipolar Disorder. These have included feeling out of control (Crowe et al., 2012) and the acceptance of diagnosis (Inder et al., 2010). However, none of this research looked solely at mania, which may not enable the full dimension of the manic experience to be explored.

A first manic episode can be a frightening, disturbing incident with devastating results for the person experiencing it (Licinio, 2005). Accounts of the first hand experience of mania by physicians with Bipolar Disorder have highlighted how the medical explanations given to their manic experiences while in an episode were not able to capture the profound spiritual questions the experience was asking of them. This led to a deep sense of dissatisfaction with the treatment they had received (Whitney, 1998; Licinio, 2005).

Only one paper has looked at the experience of mania specifically. Russell and Moss (2012) explored the distinction between mania and happiness in people with Bipolar Disorder. Their research suggested that experiencing mania led to participants struggling with the challenge of having to question their mood states, whether they were high or happy, and whether this meant illness or wellness. This suggests that the experience of mania could lead to specific considerations and issues in the person who has experienced it, but there has been too little research to be conclusive about this.

2.2.4. Rationale and Aims of Current Research

While research is growing into the lived experience of Bipolar Disorder, as a whole, research into the experience of mania is rare. Little is known about the unique aspects of experiencing mania as it is usually researched in conjunction with discussion about the other pole of the Bipolar Disorder experience, depression, or in

terms of a research aim that focuses upon an area like recovery. Without research into the lived experience of mania, the full complexity of what that experience feels like cannot be understood.

The aim of the current research is therefore to explore and better understand the lived experience of mania in people with a diagnosis of Bipolar Disorder in an effort to inform clinical practice.

2.3. Method

2.3.1. Research Design

A qualitative research design was selected to meet the aims of this research due to its exploratory nature. Interpretative Phenomenological Analysis (IPA) was selected as the methodology due to its emphasis on a detailed description of a person's experience and the meaning that particular experiences hold for them (Smith, Field & Larkin, 2009). IPA is phenomenological as it seeks to understand the participants' account from their own perspective rather than examining it from an objective reality. This perspective also understands and recognises the contribution of the role the research plays in the analysis and interpretation of each participant's account of their experiences. IPA is now a well established methodology for those seeking to understand the experiences of those with a wide variety of health conditions (Brocki & Weardon, 2007).

2.3.2. Participants.

Participants were recruited by contacting mental health teams in two NHS Trusts in England who identified eligible potential participants. People who were identified by

the teams as fitting the inclusion and exclusion criteria (see table below) were invited to take part in the research.

Table 2.1.

Participant Inclusion and Exclusion Criteria

Inclusion Criteria	i) Diagnosis of Bipolar Disorder from a consultant psychiatrist ii) Be in remission of Bipolar symptoms iii) Be over 18 years old iv) Have experienced a manic episode within the last 12 months
Exclusion Criteria	Non English speaking

Six participants were recruited, three male and three female. Six was considered an appropriate number for this IPA study as it allows for a detailed interpretative account of each individual case, while also allowing for an examination of similarity and difference, convergence and divergence (Smith et al. 2011). All participants described themselves as white British and were aged from 24 to 41. All names mentioned in the analysis are pseudonyms.

2.3.3. Materials

A semi structured interview schedule was utilised (appendix F) as recommended for IPA methodology (Smith et al. 2011). This was developed to use a flexible, non-leading, open ended framework for questioning to allow the participant to lead the interview with the information and experiences most important to them. Questions were designed with the consideration of the research aims, existing information in the literature and liaison with the supervision team.

2.3.4. Procedure.

2.3.4.1. Ethics.

The research was designed in concordance with guidance by the British Psychological Society (BPS, 2010). Ethical approval was gained from Coventry University and a NHS Research Ethics Committee (Appendix G). The study was registered with the NHS Research and Development (R & D) departments of Coventry and Warwickshire and Worcestershire.

2.3.4.2. Recruitment

Two National Health Service mental health teams were involved in recruitment of participants. Potential participants who were identified by their psychologist as fitting the inclusion criteria were provided with an information pack. These included a participant information sheet (Appendix I) and details of how to opt into the study by contacting the researcher. A total of seven potential participants contacted the researcher. After telephone contact with potential participants, six of the potential participants decided to participate. Informed consent was ensured by providing the participant with ethically approved information about the study.

2.3.4.3. Interview Procedure

Interviews took place either where the participant received their Bipolar Disorder related care or in their own home depending on participant preference. Participants were provided with the participant information sheet to review once more and given an opportunity to ask the researcher any questions. Written consent was then provided by the participant (appendix J). Interviews lasted between 45 and 90

minutes and were audio recorded. Following the interview participants were given the opportunity to ask the researcher any further questions.

2.3.5. Analysis.

Following each interview, audio recordings were transcribed verbatim. Identifying information was removed and participants provided with a pseudonym. This data was then analysed according to the IPA method detailed by Smith et al. (2011). An excerpt of a transcript with initial coding is included (Appendix K), as well as the themes developed and clustered for one participant (appendix L). This process was repeated for all participants before patterns across cases were considered and overall themes elicited. These were then clustered to provide sub-ordinate themes within super ordinate themes.

2.3.5.1. Validity of the Study

Yardley (2008) describes criteria for demonstrating the validity of qualitative work. These include recognising and considering the role of the researcher, transparency of analysis, coherence across aim, method and analysis, and reflexivity throughout the research process. These criteria have been used throughout the research to enhance the validity of the study. All stages of the analysis were discussed with the research supervisors who are experienced with IPA methodology and the participant group.

2.3.5.2. The Researcher's Position

The researcher was a trainee clinical psychologist who had no prior involvement with the NHS departments involved in the recruitment to the study. The hermeneutic underpinning of IPA methodology requires the researcher to be committed to understanding her own preconceptions and how these may impact upon the

interpretative engagement with the data. Two methods were used to bracket the researcher's assumptions during the analytical process. Firstly a bracketing journal was kept in order to explore and note issues which may affect neutrality. Secondly, a bracketing interview, where the researcher answers their own interview schedule, was conducted with a psychologist colleague familiar with bracketing interviews. This was used to generate a heightened awareness of assumptions held by the researcher about the type of answers that may be generated by participants (Rolls & Relf, 2006). Prior to the research starting the researcher anticipated that the experience of mania would have both positive and negative aspects. The researcher felt that some of the positive aspects may be an increase in creativity, while the negative may be a loss of control. This is possibly as a result of the common conceptions and presentations of people with Bipolar Disorder in popular culture around the time the research took place (Spring 2013). As the researcher was trained in clinical interview skills as opposed to research interview skills there may have been a possibility that her interview style, manner and personality influenced the participants' response styles. The researcher acknowledged this potential influence and considered this as part of her analysis.

2.4. Results

Following analysis of the data, three super ordinate themes emerged; 'if you could bottle it and sell it', 'the darker side of mania' and 'Loss- past, present and future'. These and the subthemes are detailed in Table 2.2 and discussed narratively with consideration to the convergence and divergence within themes.

Table 2.2

Superordinate and subordinate themes.

Super ordinate Theme	Subordinate Themes
Theme 1 If you could bottle it and sell it...	It's like a drug Becoming super human
Theme 2 The Darker Side of Mania	Never fitting in Fear of stigma Control and change Culture and mania
Theme 3 Loss – past, present and future	Loss of the future Who am I? Loss of family

2.4.1. Theme 1 . If you could bottle it and sell it...

All of the participants described aspects of their mania which were exciting or interesting to experience, both in relation to themselves and the reactions of others.

This theme is discussed below in the subthemes of 'It's like a drug' and 'Becoming super human'.

2.4.1.1. Theme 1a 'It's like a drug'

Four of the participants used the metaphor of drug taking to describe aspects of their manic experience. Lyndsay and Ed described the feeling of being manic as that of being on drugs.

“your mind feels like it's more able to think of things, it's a really weird feeling, what it must feel like if you take loads, if you take drugs recreationally and they are the ones which make you feel like happier”

Lyndsay (77-80)

Although Lyndsay has not used illicit drugs, she uses shared cultural knowledge about the effect of certain kinds of drugs to emphasise the happy feelings she has when in a manic state. For Jodie and Ed, who spoke openly about their drug use throughout the course of their interviews, being manic was contrasted with the

effects of these drugs. For Jodie in particular, her experience of mania, especially the build up to it was far superior to any drug that she had taken.

“The build up towards, when it get serious, is actually quite good, if you could bottle it and sell it, it would be worth millions”

Jodie (471-472)

Here Jodie emphasises that the build up to a manic episode is very enjoyable by discussing its worth to other people. Mania’s value is reinforced by the notion that others would want to purchase this as a product. Paul echoed this sense that the manic experience had commodity value but this was tempered by Paul’s feelings about the negative parts of this experience.

“I mean, like I say the actual mania is really enjoyable you know, it’s something you crave. Like someone we know once said if you could bottle it and sell it, it would be like the number one best seller you know? It’s not, it can lead to you getting into lots of trouble”

Paul (117-120)

In addition to the notion of value of mania, there is also a sense in these extracts that there is a wish to take control of the manic experience, which the participants can choose to ‘take’ mania, as so control the negative aspects associated with their experience.

Jodie described the compulsions she experienced as part of her mania in terms of a drug addict coming down.

“If I can’t fulfil a manic episode it’s like coming off drugs, its horrendous like I will be just insane if I can’t do whatever it is that I want or it feels like I need to do and people don’t understand”

Jodie (606-609)

Jodie frames her manic behaviours as ones that she needs to do in order to keep her high going and how being prevented from this can cause an even larger detrimental effect on her than the actions she may do while manic.

Using the metaphor of drug taking, participants use culturally shared understandings of what it's like to be on drugs to convey the nature of the experience of mania to the interviewer. The sense of the value of mania, as a bottled and sold commodity that everyone would want is emphasised. Mania is also linked with other, darker elements of drug taking, such as making participants act in a way they do not like, being artificial, addictive and causing problems.

2.4.1.2 Theme 1b 'Becoming super human'

Five of the participants described an increase in their abilities to cope with certain aspects of their world when they were in a manic episode. This increase in abilities covers a variety of areas that the participant values. Ed, for example, considers how he is when he is manic.

“I think, some of it just contributed to a general feeling of confidence within me, I wasn't getting on with my parents so well so there was a lot of emotion going on there and I got into this frame of mind I'm on my own now, I've finished with my girlfriend, I'm fine that's finished that's gone, I'm strong and on my own moved out of home that's great, my brothers gone away but that's cool I can be myself now, step into his shoes a little bit, he was a bit of a strong character so there was all that going on in my head”

Ed (28-35)

For Ed, mania provided him with the strength and confidence to deal with a lot of changes and loss that were happening in his life. However, there is a contradiction in Ed's statement about the ownership of this strength in the lines 'I can be myself now, step into his shoes'. Holly describes her experience of mania as something that gave

her the ability to push and drive herself in a way which fit with her career aspirations.

“because I’m self employed its really helpful just I’m a writer you go for jobs that you’ve got no self doubt when you’re up, just think I can do that you are really ambitious and go for the most ridiculous jobs and half the time you get them cos you’ve got the drive it can be a push”

Holly (141-146)

For two of the participants in particular, mania was associated with an almost supernatural surge in their abilities. Paul, for example, discusses how his ability to analyse the world around him seemed to increase to the point where he was able to predict what would happen.

“I suppose the thing with mania is it’s almost like, especially cos you pick up on every tiny little thing and your mind goes through it and analyses it within the blink of an eye and strangely enough it almost does become a sort of psychic ability, cos your mind is working in such a fast way”

Paul (297-301)

When Paul’s mania reduced he experienced a deep sense of loss as he started to feel human again.

“I suppose it was a bit of identity crisis at the time, erm, being brought back down to earth after having all these grand desires and big goals and delusional thoughts. It’s like I dunno its almost like you are being told you are human again and got to have all these limitations on you I suppose the realism hit me a little bit I wasn’t designed for greater things you know”

Paul (106-112)

For Paul, being human brings a series of limitations which are simply not present when in his super human manic state. This sense of loss will also be explored in later themes.

Holly also described the way she felt while manic as super human.

“the manic side in some ways is so desirable so you kind of don’t think there is anything wrong with you, you are untouchable, you almost feel like superhuman”

Holly 37-40)

By emphasising the sense that she becomes untouchable and superhuman while manic, Holly communicates how attractive that state may feel.

Five of the participants described how being in a manic state can have a positive effect on different aspects of their life that they value. When looking at the two sub-themes together mania can be seen as an addition to the lives of the participants.

Mania is an enhancer of both day to day life and ability, allowing for a heightened experience of the world. While this experience is valued by the participants in many ways, for Paul, Holly, Ed and Jodie the experience of mania is also risky, dangerous and addictive. The impact of experiencing mania will be explored in later themes.

2.4.2. Theme 2 ‘The Darker Side of Mania’

In theme 1 some of the positive aspects of mania which the participants identified were discussed. Through this theme the sense that the experience of mania had many costs was prevalent even while the participants enjoyed aspects of the experience so much they became addicted to it. This theme ‘The Darker Side of Mania’ explores the darker side of being a person who has experienced mania through the sub themes of ‘never fitting in’, ‘fear of stigma’, ‘control and change’ and ‘culture and mania’.

2.4.2.1. Theme 2a ‘Never fitting in’

Four of the participants identified ways in which their experience of mania exacerbated an already existing sense of difference they had to the world around

them. Although the extent to which this affected the participants varied, in each case their experience led the participant to ask existential questions about where and if they fit within their identified peer group.

“I look back over my life and I can see now deep down, I’ve always been different psychologically, spiritually, compared to the environment I grew up in. I’m different even when I’ve been away travelling around people who enjoy the same sort of things that I do, I still never quite fitted in, I never quite fitted in with anything”

Ed (436-441)

Throughout Ed’s life he has felt different to those around him, and experienced a sense of not belonging. The fact that he has experienced mania has strengthened his sense of not fitting in, but has also raised queries for Ed about how he fits into the mould of someone with bipolar.

“My body and mind is baffling and I’m wondering if I’m the right kind of person for your kind of work”

Ed (391-392)

In this short extract, Ed again emphasises the things that make him different and would exclude him as being appropriate for the research he is taking part in as he cannot fit into the diagnostic group he has been assigned to. Being different is a powerful part of Ed’s identity, and his experience of mania has both strengthened his sense of difference and reduced the places he could go to for support and exploration of his self. There is also a sense of grandiosity in the way Ed positions his difference which may be helpful for supporting his sense of self esteem.

Lyndsay has had to occupy a position where she emphasises her non normal status and identifies as having Bipolar but cannot occupy the same space as people with severe Bipolar as she feels she does not fit with them. The theme of not fitting in is

reflected in the medical care Lyndsay has received as she feels the medical profession is abandoning her.

“It feels like they are saying well if you were a lot worse then maybe I’d go to like do something, you’ve obviously got this problem but the medication that I give you doesn’t seem to do much then I don’t really know how I can help you”

Lyndsay (265-268)

Not fitting into a peer group or following the conventions of a group has not always been a negative experience for all the participants. Holly believes that when she began to experience manic episodes in her late teens, this transformed her from being a quiet shy person to one who was extrovert and outgoing.

“when I was manic I didn’t ever think to go to the Doctors or get diagnosed well I didn’t think it was a problem because I was such fun and productive and creative and just life and soul of the party and everyone thought this is just who Holly is”

Holly (5-9)

Holly’s describes her social relationships as being strengthened by her experience of mania, making her more attractive and interesting to others. Holly also positions herself outside of her peer group here, as the life and soul of the party so in this respect Holly’s not fitting into the norms of her peer group is beneficial for her.

“I’ve got friends, it was almost like they were disappointed when I settled down a bit to some degree, I think yeah, kind of, they almost, you don’t see them as much it could be because I’ve changed the stability isn’t as interesting”

Holly (273-276)

While Holly has started to become similar to her friends as she has settled, this has actually been detrimental to her friendships as she has become less interesting to them. It has also led her to question what it is about her that is interesting to others.

For Ed and Lyndsay, their sense of not fitting into their peer groups, not being normal in some way has been strengthened by their experience of mania and has reduced the areas in which they can seek help. Alternatively for Holly, her experience of mania made her an outlier in her social group, which had positive effects on her relationships.

2.4.2.2. Theme 2b 'Fear of stigma'

The theme of the fear of stigma was discussed by the participants.

“I mean when I meet people for the first time obviously I don’t tell them about my illness, although people are very understanding about it, it’s not want you want to be part of a first impression. But because I have been out of work for so long people often wonder why I’ve been out of work for so long and it’s quite hard to explain without bringing the mental illness side of things in”

Paul (442-447)

Paul makes it clear that he doesn’t want his manic experience to be part of the way people think about him, and his use of the word ‘obviously’ indicates that he feels this is the socially accepted way to think about this.

“it’s easier to speak with people who have had similar experiences, because they may understand more where you are coming from, sometimes when you tell people about it you don’t know how people are going to react or you feel people might judge you in a certain way if you tell people about it”

Lyndsay (121-126)

The fear of other people’s reactions to mania is a consideration for Lyndsay too, but she finds it easier to talk to others who have had similar experiences. For some of the participants this didn’t feel possible leading to a sense of loneliness.

“I’ve always liked the idea of that (support group) but it’s never really been there’s the bipolar support group they meet here, it doesn’t really exist, I know for a fact that I just kind of get on with it, I don’t really go looking, I don’t go talking about it”

Ed (495-49)

For Paul, Lynsday and Ed, the fear of stigma was reflected in their considerations of stigma and talking about their experiences with others. All held fear about what that would mean for them and restricted their communication about themselves, as well as the opportunities for further support. There was also an indication in the narratives that participants felt other people would not be able to understand their experiences. These ideas were also reflected in the accounts of the other participants.

2.4.2.3. Theme 2c 'Control and change'

All of the participants discussed issues which fit into the theme of control and change in their interviews. Five of the participants felt that they had some control over their future experiences of mania although there was also ambivalence and uncertainty in these discussions.

“I think a lot of it is my control, even if it’s probably not, I have to think that it is otherwise you wouldn’t want to achieve anything in your life, you would just roll over and I’ll just not do anything then”

Jodie (827-829)

For Jodie a sense of autonomy and control are vital for her motivation and desire to survive. Although Jodie’s need to believe in her own control is so strong she feels she would give up without it, her statement is tinged with uncertainty.

Paul also reflected an uncertainty when he was talking about his future.

“I’ve got to be my own driving force and it’s like I’ve been thrown in at the deep end to the choices are swim strongly or to drown. I think it’s going to go one way or the other, either I’m going to sink down or I’m going to rise up but who knows time will tell. It’s just to get myself back to success and achievement again is going to be an uphill struggle but it is something I am going to have to push towards again.”

Paul (544-550)

Paul describes how he needs to be the one driving and pushing himself to get back to who he wants to be. At the same time Paul is almost fatalistic when describing the

consequences of not succeeding, he will drown and sink if he does not manage to get himself out of where he is, echoing Jodie's sentiment that she will just roll over (and die) if she can't get to where she needs to be.

As well as discourse about control, there was also discussion from the participants about how that would happen and what would need to change and who is responsible for that change.

"Bipolar can be something that is not normal if I don't take the right steps, if I don't take my meds then my mood fluctuates, if I don't take my meds then I start drinking there's only going to be one outcome that I'm going to be unwell that I'm going to be sick and its quite a sobering thought that I've got that barricade that's immovable now that I can't, I'm not going to be the person that I was there's no way that's going to happen"

Jason (525-533)

Jason suggests the negative consequences of not following the restrictions he imposes upon himself but there is also a sense that Jason is overwhelmed by these restrictions in the use of words 'immovable barricade'.

"So I think you have got to kind of put the brakes on a lot, which is actually really frustrating cos a lot of the time I just want to do stuff and I feel like, as I say, I monitored it and managed it effectively but something you get so frustrated watching everything, being really careful about what you are eating and what you are doing"

Holly (561-566)

Holly also expresses her feelings about self imposed changes she has made to keep herself well. There is a sense of tension between the limitations of staying well and the limitations of becoming manic.

For the five participants who discussed control as something they felt they needed to get over their moods, there was a strong sense that they were responsible for the changes that this may involve. This sense of personal responsibility seems tied to the sense of taking or having personal control and autonomy over the experience of

mania but also neglects to note the role that other support structures could play in these changes.

2.4.2.4. Theme 2d 'Culture and mania'

Five of the participants discussed how representations of mania and Bipolar Disorder in the media, culture and wider society had influenced their beliefs and attitudes towards themselves.

“its difficult to have any ambition about things because you don't know what your boundaries are, I wish there were more role models”

Jason (570-572)

Here Jason emphasises why media representations of Bipolar Disorder are important to him. Jason is living in uncertainty after his experience of mania, and he is unable to start making aspects of his life certain as he feels he has no one to show him how to be after his experience.

Jodie described how people around her, her doctors and her wider cultural experiences of mania have demonstrated an ignorance of the reality of her experiences. For Jodie this lack of understanding is frustrating but it also creates a sense of fear.

“I think when you are manic it's so hard just to spot the signs from everyone else's point of view it's like 'oh she's being really productive and you know she's not depressed anymore she's obviously getting on' and it's a positive compared to the depression, and I don't think people pick up on it at all but personally from my point of view I don't know when, and even now I struggle, and it's still one of my main concerns that I don't always know when I'm leading up to a manic episode or when I'm even in one, cos you are productive like I said, you don't see it at the time as being dangerous”

Jodie (177-188)

Here Jodie describes her concerns that she will become manic again and that she is unable to spot it. This is exacerbated by her sense that others around her will not

recognise her mania either, so not only can Jodie not trust her own feelings she cannot rely on other peoples help.

Some participants noted how identifying with cultural representations of mania and Bipolar Disorder helped them. For Holly, the identification with media figures that had been diagnosed with Bipolar Disorder helped her to both separate Bipolar Disorder from other mental illnesses which she found problematic, and to reaffirm some characteristics she saw in herself as special.

“Yeah I tell people, I feel I need to, I can’t just say it simply, I have to explain but so was Kurt Cobain and so was Jjimmy Hendrix and so was Stephen Fry and you kind of feel you have to bring up these other people as kind of examples of the creative thing and, or I make some joke about how we’ve all got higher IQs and we are more creative and because I feel I have to overcompensate for, but you don’t want people to think you are mentally ill”

Holly (508-515)

Here Holly describes how she uses media knowledge about mania and Bipolar Disorder to both protect herself from others potential stigmatising reactions to her experiences, and to construct an identity for herself which includes desirable characteristics.

2.4.3. Theme 3 Loss – past, present and future

Loss was a central theme in the participant’s discussions of their lives post mania. Participants described their losses and the questions this raised about what comes next for them. The theme of loss is discussed using the sub themes of ‘loss of the future’, ‘who am I?’ and ‘loss of the family’.

2.4.3.1. Theme 3a ‘Loss of the future’

For some of the participants the experience of mania had caused them to re-evaluate their hopes and dreams for the future. This re-evaluation was tinged with a sense of loss, that they had to let something of themselves go, as well as a sense of fear.

“I don’t know, I think the illness has made me a bit more realistic about what I’m going to achieve in life and that’s quite disappointing, The fact that you realise not everyone was put on this earth to do great things, I mean everyone was put on this earth, is different, everyone wants to leave their mark on the world. But I think there are some people who are just designed to exist rather than...”

Paul (514-520)

Here Paul describes how his experiences of mania have made him reconsider his ambitions for life, and the sense of disappointment he feels at his loss of them. In this passage Paul considers the reason for his existence in the world and how his experiences have changed his view about why he is here.

For Jodie, the losses associated with her manic experiences are closely tied to an anxiety about mania happening again, and how this might be of further detriment to her goals, ambitions and ultimately becoming the person she so wanted to be.

“I can’t live like that because I would just kill myself, cos it’s not like Jodie from, from when I was younger, like I’ve always wanted to achieve, I’ve always wanted to do something with myself and have a great career”

Jodie (832-835)

Holly experienced a number of losses which affected her feelings towards her manic experience when she was diagnosed as having Bipolar Disorder.

“I think it’s coming to terms that you will have this for life that’s quite difficult, with depression I thought this, I would get through cos I’d done a lot of work, a lot of therapists and stuff and things like this and then yeah, I think it’s more the long term idea that there is no cure is there? I think you can have remission cant you? It’s just the idea that you have got this forever that’s hard to come to terms with”

Holly (379-384)

For Holly, the change from thinking she had depression to seeing her manic experiences as part of a whole illness was very difficult and meant she lost the idea of being able to find a cure, something which she had previously been striving for.

The theme of loss was prevalent in many of the participant's accounts of their lives in the aftermath of their manic experience. For Paul and Jodie this was centred on a loss of their expected future selves and for Holly, being diagnosed as having Bipolar meant the loss of a cure for her depression. These losses have led to all the participants re-evaluating who they are and what will happen next which will be explored in the next two themes.

2.4.3.2. Theme 3B 'Who am I?'

For some of the participants the experience of mania caused them to question the very core of their personality.

Ed continued his narrative about difference by using his experience of mania and being diagnosed with Bipolar to question what was it about him that made him susceptible to becoming manic. Ed has searched for answers about his experiences by talking with health professionals.

“I went to this psychiatrist recently, I wanted to check in and I wanted to talk to him about this dopamine thing and I spoke to this doctor and he just said look there is no way we can get inside your brain and find out exactly what's going on with the circuitry, the technology doesn't exist, and if it did what could be done?”

Ed (349-354)

The technology to answer Ed's questions does not exist and health professionals are unable to help him. Ed is therefore left with many questions about why he is as he is.

For two of the participants, the theme of ‘who am i?’ was reflected in their struggle to separate out aspects of their personality from the effects of their mania.

Jodie reflects on her the behaviour she exhibits as part of her manic experiences.

“When I’ve come out of an episode, like I don’t even know what I believe in especially when you have been manic, the promiscuous behaviour, the ridiculous behaviour, putting yourself in situations which are like dangerous, not caring about what other people think of you, I do have that in me anyway but it’s like that not Jodie or is that Jodie? I just don’t know anymore, everything I thought I knew about about Jodie who wouldn’t do that I’d just done so obviously I didn’t stand for anything, I haven’t really got any morals.”

Jodie (732-740)

Here Jodie describes her struggle to reconcile the behaviours she did while manic with her own values and beliefs. By talking about herself in the third person Jodie is attempting to determine what is part of her core self and what isn’t, but finds this too much of a struggle as she feels that if she really didn’t believe in doing these actions, she still wouldn’t do them while manic. Jodie concludes that she must be a person without morals as she is capable of acts she finds degrading. In this passage Jodie appears to see her behaviour while manic as belonging to her, even though she finds it distasteful. However her feelings of ownership of the mania differ throughout her account.

“I don’t think you can ever do a list, bipolar, Jodie, and write them down either side bullet points cos it’s never going to happen, I think you have just got to draw a line under it otherwise I’ll, and still how do I think about it, probably once every two weeks, I’m like god is this me I don’t know anymore.”

Jodie (725-730)

Jodie finds the separation of Bipolar from her core self an impossible task and describes how she has tried to become resigned to never knowing, however she still finds herself questioning aspects of her identity on a regular basis.

Holly has also struggled with the idea of what is her personality and what is an effect of her mania.

“But when I found out that it was a disorder, at first it was really hard to come to terms with cos you think all the, when you’re creative and ambitious and I thought actually that’s wrong even though it can be really good, could see it was destructive its quite hard to admit that actually that, you know, something that erm I thought it was my personality but actually it’s not its symptoms of a disorder”

Holly (350-355)

For Holly, creativity and ambition are two highly prized characteristics. The possibility that these things aren’t hers, that they belong to an illness, is a very difficult to accept. Holly is unable to see herself as a whole, rather she is trying to separate out what belongs to her and what belongs to Bipolar and the sense that these much desired characteristics are not hers, or wrong because they belong to Bipolar is very upsetting.

All three of the participants questioned what was theirs and what belonged to mania or Bipolar. A question of knowing what they were the owners of in their own personality seemed to be very important, but at the same time there was a realisation that this is a question that might never be answered, leaving the participants in a position of uncertainty.

2.4.3.3. Theme 3c’ Loss of the family’

For four of the participants, their manic experiences had impacted on the way in which they related to their roles within their family unit. All of these participants experienced some loss and grief at their changing role.

“I wouldn’t say I’ve lost them but relationships have diminished, like me and my step mother used to be a lot closer, we used to get on a lot better but now I get the impression she doesn’t even like being in the same room as me. Which

I can't really blame her cos I did take liberties for quite a long time yeah and she almost had to be the driving force behind me"

Paul (260-265)

After Paul's experience of mania, he experienced a loss of motivation. Paul's step mother provided support with this; however, this ultimately led to a loss of closeness in the relationship.

"their view has definitely changed, like I said, they just, I don't know, don't wrap me up in cotton wool, that's not the thing, literally it's like a million questions about me doing the slightest thing, and it really drives me up the wall, it just drives me insane basically, which I know why they do it but I think sometimes its case of it causes a lot of friction now because of that episode"

Jodie (427 -432)

Jodie, in her use of 'drives me up the wall' emphasises how frustrating she finds her situation with her parents. Jodie notices that her parents now no longer trust her as they fear her actions will cause her to return to her manic state and so they have become hyper vigilant to her.

Two of the participants were parents and the theme of loss of the family was evidenced in their discussions of how their manic experiences had affected their ability to be parents. For Holly this was especially poignant as she was hoping to conceive again but had experienced a relapse of mania when she had stopped taking her medication.

"cos we want to have a baby next year, the thought of it, which is another reason I was trying to lower my medication because you don't want to get pregnant when you are on medication, so the thought of if I can't have my medication, if I can't cope or what happens if I get post natal depression and the triggers an episode or what happens if I get manic or really depressed when I have a baby"

Holly (759-764)

Here, Holly is almost overwhelmed by all the potential things that could go wrong and what it might mean for her mental health if she were to have another child. Jason worries about his experiences overwhelming that of his children.

“ I don’t want my kids to see the worst of me, I don’t want to their story just to be about me, I want them to make it, I want them to be exceptional”

Jason (484-487)

For Jason, it is important that his children are able to have their own lives, and that their experience of childhood and their potential is not lost due to the impact of Jason’s experiences. Jason’s father suffered from Bipolar disorder which has influenced the fear Jason feels at the potential impact of his experiences on his children.

“I only had a fear of being ill because I never want to hurt my family the way I got hurt when my dad was ill”

Jason (511-512)

Paul, Jodie, Jason and Holly identified a number of losses related to the family as a result of their experience of mania. For Jodie and Paul there has been a change in the way their family views them, and these changes have resulted in a perceived reduction in support. For the participants who are parents, their experience has shaken their faith in their ability to be a parent to both current and future children.

2.5. Discussion

This study explored the experiences of mania in people who had been diagnosed with Bipolar Disorder. Its aim was to explore and better understand the experience of mania which may be used to inform clinical practice.

Three themes emerged from the data and these will be discussed with relation to existing literature before the consideration of the clinical implications of the findings and the study limitations.

2.5.1. Discussion of the Findings

2.5.1.1. Theme 1 'If you could bottle it and sell it...'

This theme considered the desirable effect of mania as an additive to the participant's existing skills, abilities and experiences. Previous research has found that Bipolar Disorder is seen as an enhancer of the existing self, enriching the qualities that person possesses and in some cases can be seen as a gift one has been given (Lobban et al, 2012). Participants in this study discussed mania in terms of something that they desired to take rather than to be given indicating a sense that although they wanted to experience mania, they wish to have more control and autonomy over it.

There was a sense of ambivalence in the participants' descriptions of their enjoyment of their mania, as there was recognition that while you were manic it was a great feeling but it was also an experience that could lead to destructive consequences. Previous research has also found themes of ambivalence towards the experience of mania. Russell and Moss (2012) found conflict between participant's enjoyment of the manic state and their fear of the consequences of it while Fernandez et al (2014) found that participants found their own behaviour when manic both exciting and frightening. This ambivalence towards the manic state could be a major factor for participants when they are thinking about strategies of recovery. Veseth et al (2012) found that participants, even when explaining the terrible consequences of their manic behaviour would still favourably reminisce about how the mania felt, making

it difficult for them to engage in activities or take medication which might reduce this. For the participants in this study, while shame, guilt and risk were discussed in relation to their manic experiences, there was a strong sense of how fantastic their manic experience had been.

2.5.1.2. Theme 2 The darker side of mania

Participants reflected on the different ways that their experiences of mania had negative consequences. For some of the participants, not fitting into their peer groups had been a part of their life experience since their teens which was exacerbated by their manic experiences. Research into young people who have developed Bipolar Disorder in their teens has picked out similar themes of not fitting in to peer groups and questioning a sense of belonging (Inder et al 2010). Bipolar Disorder is thought to develop during the teen years and have an effect on personality development and neuro-cognitive functioning during this crucial period (Pavuluri, West, Hill, Jindal, & Sweeney 2009) however it is often not picked up on until many years later. It is possible that for some of the participants their sense of not fitting in developed because of their prodromal Bipolar Disorder.

Being isolated from society due to the perceived stigma they feared experiencing was a theme which was mentioned in all of the accounts of the participants.

Participants described how they chose when and who to disclose their experiences to as a means of reducing potentially damaging consequences. This notion of 'judicial disclosure' has been identified as a coping strategy in a number of qualitative studies looking at stigma in Bipolar Disorder (Hawke et al 2013).

Being out of control has been identified as a core concern for people with Bipolar Disorder who are beginning the recovery process (Crowe et al 2012). In this study,

participants detailed their need to take control of themselves as part of moving on and their future. Fernandez et al (2014) found that the notion of taking control was a key factor in the redefinition of identity of participants with Bipolar Disorders experiences of recovery. The participants in the present study described their need to take charge and ownership of the changes they had identified, at once isolating themselves from other sources of help but gaining a personal autonomy that Bipolar Disorder had taken away from them. Taking control over self management has been found to be an important step in creating order in the uncertain lives of people with chronic illnesses (Kralik, Koch, Price & Howard 2004, Koch, Jenkin & Kralik 2004). While sources of support involving others have been identified by people with Bipolar Disorder as helpful (Doherty and MacGeorge, 2012) the process of taking control over their recovery might be an important step for the participants in this study.

Cultural understandings of mania affected how the participants felt placed and understood in society. Participants described how mania was hidden from mainstream society, as information about it was not readily available nor part of the language used to describe mental health issues. Mainstream media's portrayal of mental health is often focused around themes of dangerousness and criminality (Stuart, 2006) and they rarely portray recovery or positivity about mental illness (Nairn, 2007). Participants described finding little information in the media about what mania was before they received a diagnosis and noted few positive role models for recovery post diagnosis. Cross and Walsh (2012) have described the process of self disclosure of celebrities experiences as a coming out, similar to gay people publicly declaring their sexuality. This can have both a positive impact, such as bringing the term Bipolar Disorder into the mainstream; or negative, such as when

celebrities with a history of disturbed and chaotic behaviour are diagnosed.

However, as Cross and Walsh noted, these discourses do not tend to focus on the symptoms of mania, unless they are fairly lurid. Participants described being frustrated at this lack of information, and wanting more discussion about mania and Bipolar Disorder in mainstream culture, particularly focused on recovery.

2.5.1.3. Theme 3 'Loss- past present and future'

Participants' loss of their expected futures, self identities and family structures is the final theme emerging from the data. The theme of loss in the existing literature has focused on the losses associated with a diagnosis of Bipolar Disorder and how this has led to participants questioning and reformulating their identities (Fernandez et al, 2014).

In this study the experience of mania led the participants to re-evaluate themselves, questioning what part of their personalities were their own, adapting to a diagnosis and considering what will happen in their future. Participants struggled with how much the manic experience may overshadow them, or take aspects of their identity. Participants also discussed doubting parts of themselves that they liked, as belonging to them, a theme which has also been found in research into recovery (Michalak et al., 2011). Low self esteem in people with remitted Bipolar Disorder has been found to be similar to those of people with depression (Knowles et al., 2007). Having to question whether aspects of the self that one once thought of as positive but are now possibly attributed to a disorder may impact on this low self esteem.

2.5.2. Methodological Limitations

IPA methodologies draw on small samples where detailed idiographic examination of participant experiences can occur. However due to its use of small sample sizes IPA does not pertain to be able to make generalisations to the wider populations.

The participants in this study were all white British and self selected. This may be a source of bias, with those choosing to participate having certain motivations to do so. Participants varied in the types of Bipolar Disorder they were diagnosed with and therefore had a range of different severities of manic experiences. This severity type may have influenced how problematic the consequences of their actions during mania were and made the group less homogenous. However, there is disagreement in both research and clinical practice about where the distinctions and cut off lies between the various types of Bipolar Disorder and the dimensions of mania within them. All the participants self identified as having had manic experiences.

Recruiting more participants for this study, or ones with more similar Bipolar Diagnosis may have enriched the findings, although the breadth and depth of experience elicited by the six participants in this sample provided rich data with clear evidence of divergence and convergence.

2.5.3. Clinical Implications

This research has indicated that for some people with Bipolar Disorder the experience of mania is wonderful but it is associated with a number of costs which create ambivalence towards the loss of this experience through being diagnosed and treated for Bipolar Disorder. The understanding that an experience that a person

holds dear is due, at least in part, to a mental health problem causes great questioning of identity and grief at its loss, as well as making people feel alone and isolated.

An awareness of the difficulties experienced by people after they have experienced mania and the ambivalence they may feel towards labelling their experience a disorder, or indeed wanting to stop it is indicated for professionals. Interventions for Bipolar Disorder need to be aware of and fully compensate for these difficulties. Current psychological interventions for Bipolar Disorder are varied but the ones recommended tend to focus on a psycho educative approach which is complimentary and encouraging of medication (Miklowitz, 2008). However, psycho educative approaches can often be ineffective as they assume that with enough psycho education people will manage their illness appropriately while not taking into account the individuals feelings towards their illness (Kralik et al 2004).

Alternative effective approaches to mania and Bipolar Disorder could be those which take account of loss, isolation and ambivalence and the effect this has had on the persons' identity and trust they have in themselves. By helping someone to develop a sense of trust and faith in their selves which also allows for shifting or fluid identities, such as those experienced in the manic state, the manic individual can reduce their feelings of shame, guilt and loss of identity (Potter, 2013).

2.5.4. Areas for Future Research

This topic area would benefit from further qualitative research exploring participant's experiences from different samples, from different demographics and recruited from different NHS services. This would add to the understanding of the experience of mania as part of Bipolar Disorder.

This study was designed to elicit participant experiences broadly about their experiences of mania. Further qualitative research studies looking specifically at different types of mania, different stages in the journey i.e. first manic experience or many manic experiences, or different age groups will act to contribute to an even more detailed insight into the experiences of people who have been manic. Future research may also focus specifically on people who chose not to stop experiencing mania post diagnosis, or how mania is incorporated into the self identity of those in remission from Bipolar Symptoms. Improved understanding of the specific experiences of people who have had mania is increasingly important when considering the rise in diagnosis rates of young people with Bipolar Disorder.

2.6. Conclusion

This study has explored the experiences of participants who have experienced mania and been diagnosed with Bipolar Disorder. Using Interpretative Phenomenological Analysis methodology, six participants' accounts of their experiences were analysed. Participants' experiences were characterised by the enhancing effects of mania, isolation and loss. Participants also questioned their identity and how they needed to change themselves in order to recover. Future research to understand in even greater depth as well as breadth, the experiences of people with mania will further contribute to best inform professionals and services.

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Chapter 3: Reflective Paper

Reflections on the research process as a trainee clinical psychologist.

Paper not intended for Publication.

Overall chapter word count excluding references: 2674

(These reflections are based on the initial research period over 2012 and 2013. An addendum to these reflections can be found in appendix M).

3.1. The Scientific Practitioner Model and Me

As a trainee clinical psychologist, I am encouraged to reflect on my practice.

Reflective practice is a process where reflection enables self awareness and learning (Cushway & Gatherer, 2003). I have utilised reflective practices throughout my training in order to enhance my understanding of the personal processes involved in training, and to improve my professional practice. As part of the research component of my training, I kept a reflective journal, where I documented my reflections about the research journey. This paper consists of those reflections which are organised around the theme of the ‘scientific practitioner’. A scientific practitioner is one who uses scientifically validated methods of assessment, uses a scientific model of observation, hypothesis generation and testing and contributes to the evidence base (Shapiro, 2002). This last element is described as an essential part of the clinical psychologist’s role, and is the reason I had to complete research independently while training. This paper describes my reflections about the research process, and how this experience has contributed to feelings about being a scientific practitioner.

3.2. Identity as a Researcher

I have always felt that I was accepted onto the clinical psychology training course as a result of my research background. This and my lack of what I felt was ‘proper’ clinical experience i.e. assistant psychologist work, led me to focus on my research background as a strength, especially when I felt inadequate as a therapeutic clinician. I began to identify strongly with the idea that while I may be a poor therapist, or that my skills do not lie in that aspect of clinical psychology practice, I would be excellent at the research component.

I felt a huge sense of pressure from myself to be good at research, as, in my eyes it was the only thing that made me eligible to be a clinical psychologist. A failure in this area would be a failure at the profession I had spent the majority of my life trying to be, and then, what would I do? For some people, the need to be perfect at something drives them onwards, to be continually refining and improving their work (Stoeber & Otto, 2006). I acknowledge this approach can be a trap for many, but for me, the need for things to be perfect has the opposite effect (Pacht, 1984). I run and hide, too frozen to even pick up a pen and write.

This has always been present in me, and it was something that I was aware of before beginning my training as a clinical psychologist. However, it feels that it has never been so vital for me to be ‘good’ at something than it has during my training experience, not even in my previous role as a researcher. Being perfect at research was something that I felt I had to be, and this began to cause difficulties when approaching supervisors for assistance. I also felt stuck at many parts in the research process, finding that when I reached a point where I did not know what to do, I would become frozen and fall behind while hoping that situation would work itself out.

The supervision process helped me a great deal with this issue, as I was fortunate to have a supervisor who was able to recognise what was happening for me, and help me reflect upon what I was experiencing. This helped me to become unstuck, and to make the most of the supervision process, going from asking for no assistance, and at times actively pushing supervisors away, to handing in lots of examples of my work, from short sketches to full drafts. Of course, the process of supervision and the constructive criticism that this entails is familiar to me from my clinical practice. However, supervision of my practice has always been more acceptable and welcome

for me, which I have not always found in my research practice. Upon reflection, I feel that this is because I come from a position of not being fantastic at therapy, and so welcoming the supervision I receive. Using supervision of research in the same way challenged my identity as a ‘good researcher’, which is synonymous with being independent and not needing help for me.

I am glad that reflecting on the research process has enabled me to recognise these qualities in myself, and how identifying as a researcher was affecting my ability to actually research. I feel that being a researcher is still part of my identity, but that this has moved to being part of my identity as a clinical psychologist, rather than as part of what helps to contribute to my self-worth. From these reflections, I feel that for me to be an adequate scientific practitioner in the future, I will need to make full use of the supervision process.

3.3. Practicalities and Compromises in Research

When I look back over my diaries from the beginning of the research process, I notice how idealistic I was about how my research would go. It is a very exciting time, taking the seed of an idea and growing it into a fully formed research proposal, one which I hoped would fill a huge gap in the research literature, as well as providing information that will help people from a clinical perspective. However, the nature of doing research means that practicalities and compromises happened for me, leaving my finished research looking somewhat different to that proposal.

Time is a huge factor in clinical trainee research. I was not employed where I was researching, and I lived quite far away from my participants, supervisors and ethics committees. Travelling to these destinations put quite a lot of pressure on me, as I was already very stretched with placements. Although time pressures are part of

every research project, when there are competing demands on time, such as other work obligations and so research can lose its attractiveness. My research had a deadline, which meant that I had to make certain compromises to fit this such as reducing the number of participants.

The locating and obtaining of participants was also very difficult. This was due in part to my strict exclusion criteria, but also because I was recruiting in a Trust where I had few connections and there were a number of setbacks such as supervisors dropping out and people who had agreed to help me becoming unwell. This meant that I often had to compromise my exclusion criteria and expand it, changing the nature of the project. Although this worked out for me, it changed the nature of the proposed research, which may have compromised its value. At times I would go to interview participants who had been suggested to me on the basis of the inclusion criteria by their clinician, when, upon meeting them, I realised they did not fit the inclusion criteria at all. This was very difficult to negotiate, as participants would have travelled to meet me, and I didn't want to let them down. However, I felt it would be dishonest to interview them just for forms sake.

The practicalities of research meant that my research did not match my original proposal. However, these practicalities were in part brought on by my status as a trainee clinical psychologist. In the future, my status as a scientific practitioner may also be compromised by the demands of my role and for me, I feel that I will need to carefully consider these demands before taking on research, in order to be able to do it to the best of my ability.

3.4. Communication

One of the things that I struggled with the most during the research process was communication. As a clinical psychology trainee, communication skills, both verbal and written are essential. My own special interest in working with people with learning disabilities makes the ability to learn how someone communicates and to be with them on their level, using their own language an especially vital skill. This has led me to feel that my communication skills are quite good, and I initially approached the research with confidence that I would be able to communicate with others well, in order to carry out my research.

The process of my research involved recruiting from two different Trusts, and a number of teams. In order to do this I needed to get ethical approval from the NHS, and Research and Development approval from the two Trusts. Neither of these Trusts were ones I was employed by. All of these processes involved getting information from many different sources, filling out many different forms and verbal communication with lots of different professionals, who in turn, were struggling to understand who and what my role was as a clinical trainee psychologist researcher. It often felt like the role of trainee clinical psychologist, rather than benefiting me, was providing a barrier to me being able to be an effective researcher. I felt like an anomaly. This was especially relevant when asking for supporting information for my research and development application from my employing Trust, who, due to being a very small department, are not used to dealing with many trainee researchers. Each Research and Development team I had to approach required different information for applications, and I felt like once I had mastered one type of communication, I was back at square one, trying to learn another. All of these variances of communication added to my feelings of being out of place.

From a very practical perspective, learning different research ‘languages’ is difficult, time consuming and, more often than not, something that one does without a guide. At times I felt like I was attempting translation without a dictionary. Thinking about this in terms of being a scientific practitioner, barriers to communication may prevent me from being able to do research effectively, as I may not be able to recruit the right kind of participants or to access participants who are not often included in research. In the future, when I am a qualified clinical psychologist I wonder how much the difficulty in communication between research and development departments may cause me to abandon certain research areas, or focus on different topics.

3.5. The Research Topic and Subjectivity

I was drawn to the topic of my research through the powerful experiences I had on my first clinical placement, working with a young person who had been diagnosed with Bipolar Disorder. At the time the concept of mania was totally alien to me and I found it a fascinating notion. The idea of being manic was so different to my own mood experiences that understanding it was a challenge, but it was also an attractive exotic idea, and I spent many hours wondering what my life would have been like if I possessed the potential to be manic. These fantasies were focused on the conception of mania in popular culture, such as the creative expressionist (Rothenburg, 2001). If I had experienced mania, maybe I too would have grown up to be exotic, prolific, attractive and famous! At the same time, my extensive clinical work with this person (two sessions per week for five months) helped me to understand how terrible the experience of mania had been for him, and how it had ripped through his relationships and dreams.

Upon reflection, I wonder how much my research into mania is an attempt to make amends for inadequacies in the help I provided for this young man. My first placement, as it is for many clinical trainees, was very difficult (Pica, 1998). I was working in an environment I had never been in before, which I found scary and hostile; trying to do a job which I felt woefully ill equipped to do. I recall that every 'end of therapy report' I wrote during that placement described the need for further therapy. This wasn't because of obvious clinical need or even that the people themselves felt they needed it, but in case I had 'messed it up', damaged them in some way through my actions. I found it very difficult to let that young man go, terrified about what life would hold for him, as he himself was.

When a clinical placement ends, I found having to deal with the fact that not only was I leaving a placement which I had finally got to grips with, but that I would never know what happened to the clients I had worked with as very upsetting. Of course, when a client is discharged from a service, a clinician would never necessarily see that person again, but people stay in the system and may get referred to other parts of the service, remaining 'known' in some way. However, as a clinical psychology trainee, when one leaves the placement that often means a total separation from the team and clients. In some ways this can be a relief, I have not loved every placement by any means, or every client I have worked with, but I always remain curious about what happens to them.

At the time of choosing my research topic I was unaware of any of the process I have described. I just knew that I found mania interesting and that I already had some ideas that I wanted to put into action. As I started to meet more people with Bipolar Disorder during the course of my research, I began to reflect about the conversations we had, which were often filled with intimate detail, and at times felt like I was

playing a very therapeutic role for the participants, simply by listening to them. This led me to reflect about how personal the choosing of a research topic can be.

As I used a qualitative methodology in my research, I had space to consider this, and to 'bracket' my own assumptions and feelings about the topic via a number of methods. However, I wonder how much this realisation would have come to me had I been using a quantitative methodology and not been keeping a reflective diary. Without this, my findings may have been a reflection of my own thoughts and assumptions. If I do research in the future, I think an important element of this will be for me to consider why I am drawn to a research area, and what function it plays for me.

3.6. Conclusion

Being a scientific practitioner and contributing to the evidence base were, before the research process, something I identified strongly as being part of my future strengths as a clinical psychologist. The research process has led me to reflect on this idea, and whether, in all honesty, I feel able or willing to incorporate contributing to the evidence base into my role as a qualified clinical psychologist. I have found the process of research both difficult, from an emotional point, and frustrating, when my ambitions have had to be attenuated through the practical constraints of the research process. However, I feel that I have also learnt a lot about myself and my motivational processes. I also feel equipped to deal with some of the challenges that research may pose for me in the future, and to be able to notice when I am getting into difficulties due to my own feelings. I feel that I have felt every possible emotion during the course of this research, from total joy to despair, but I am actually satisfied with the end result, and I am able to take pleasure from this. Being

reflective through the research process has also been incredibly useful as it has enabled me to be both reflective in action, and out of action, and has been a source of support, as well as a valuable learning process. This is not the end of my research journey, and I fully intend to research within my future posts as a clinical psychologist, however, I do not believe I would have come to this point without the use of reflection, so this process has also strengthened my convictions about the importance of reflective practice.

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Appendix A Submission Guidelines for the Journal of Affective Disorders

GUIDE FOR AUTHORS

Description

The Journal of Affective Disorders publishes papers concerned with affective disorders in the widest sense: depression, mania, anxiety and panic. It is interdisciplinary and aims to bring together different approaches for a diverse readership. High quality papers will be accepted dealing with any aspect of affective disorders, including biochemistry, pharmacology, endocrinology, genetics, statistics, epidemiology, psychodynamics, classification, clinical studies and studies of all types of treatment.

BEFORE YOU BEGIN

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Tables should be numbered consecutively with Arabic numerals and must be cited in the text in sequence. Each table, with an appropriate brief legend, comprehensible without reference to the text, should be typed on a separate page and uploaded online. Tables should be kept as simple as possible and wherever possible a graphical representation used instead. Table titles should be complete but brief. Information other than that defining the data should be presented as footnotes. Please refer to the generic Elsevier artwork instructions: <http://authors.elsevier.com/artwork/jad>.

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Acknowledgements

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Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

References

Citation in text

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Appendix B Search Terms Combinations

Search Terms	Web of Science	Psych Info	Psych Articles	ASSIA	Medline (OVID)	Pilots Data Base	Pubmed	Scopus	CINAHL	Embase
Bipolar* Substance* Adolescen* Mania, Substance* Adolescen* Juvenile, Bipolar* Substance* Adolescen* Paediatric bipolar* Substance* Adolescen* Bipolar* Co morbid* Adolescen* Mania, Co morbid* Adolescen* Juvenile Bipolar* Co morbid, Adolescen* Paediatric Bipolar* Co Morbid, Adolescen* Bipolar* Dual	29	21	0	5	55	1	19	15	4	33
Mania, Substance* Adolescen* Juvenile, Bipolar* Substance* Adolescen* Paediatric bipolar* Substance* Adolescen* Bipolar* Co morbid* Adolescen* Mania, Co morbid* Adolescen* Juvenile Bipolar* Co morbid, Adolescen* Paediatric Bipolar* Co Morbid, Adolescen* Bipolar* Dual	1	1	0	1	5	0	0	0	0	4
Mania, Substance* Adolescen* Juvenile, Bipolar* Substance* Adolescen* Paediatric bipolar* Substance* Adolescen* Bipolar* Co morbid* Adolescen* Mania, Co morbid* Adolescen* Juvenile Bipolar* Co morbid, Adolescen* Paediatric Bipolar* Co Morbid, Adolescen* Bipolar* Dual	0	0	0	0	0	0	0	0	0	0
Mania, Substance* Adolescen* Juvenile, Bipolar* Substance* Adolescen* Paediatric bipolar* Substance* Adolescen* Bipolar* Co morbid* Adolescen* Mania, Co morbid* Adolescen* Juvenile Bipolar* Co morbid, Adolescen* Paediatric Bipolar* Co Morbid, Adolescen* Bipolar* Dual	0	0	0	0	0	0	0	0	0	0
Mania, Substance* Adolescen* Juvenile, Bipolar* Substance* Adolescen* Paediatric bipolar* Substance* Adolescen* Bipolar* Co morbid* Adolescen* Mania, Co morbid* Adolescen* Juvenile Bipolar* Co morbid, Adolescen* Paediatric Bipolar* Co Morbid, Adolescen* Bipolar* Dual	45	31	0	3	0	0	143	29	5	110
Mania, Substance* Adolescen* Juvenile, Bipolar* Substance* Adolescen* Paediatric bipolar* Substance* Adolescen* Bipolar* Co morbid* Adolescen* Mania, Co morbid* Adolescen* Juvenile Bipolar* Co morbid, Adolescen* Paediatric Bipolar* Co Morbid, Adolescen* Bipolar* Dual	4	4	0	0	10	0	4	3	0	9
Mania, Substance* Adolescen* Juvenile, Bipolar* Substance* Adolescen* Paediatric bipolar* Substance* Adolescen* Bipolar* Co morbid* Adolescen* Mania, Co morbid* Adolescen* Juvenile Bipolar* Co morbid, Adolescen* Paediatric Bipolar* Co Morbid, Adolescen* Bipolar* Dual	0	0	0	0	2	0	0	0	0	2
Mania, Substance* Adolescen* Juvenile, Bipolar* Substance* Adolescen* Paediatric bipolar* Substance* Adolescen* Bipolar* Co morbid* Adolescen* Mania, Co morbid* Adolescen* Juvenile Bipolar* Co morbid, Adolescen* Paediatric Bipolar* Co Morbid, Adolescen* Bipolar* Dual	0	0	0	0	9	0	0	0	0	8
Mania, Substance* Adolescen* Juvenile, Bipolar* Substance* Adolescen* Paediatric bipolar* Substance* Adolescen* Bipolar* Co morbid* Adolescen* Mania, Co morbid* Adolescen* Juvenile Bipolar* Co morbid, Adolescen* Paediatric Bipolar* Co Morbid, Adolescen* Bipolar* Dual	0	0	0	0	3	0	0	0	0	0

Diagnosis, Adolescen*										
Mania, Dual	0	0	0	0	0	0	0	0	0	0
Diagnosis, Adolescen*										
Juvenile Bipolar*	0	0	0	0	0	0	0	0	0	0
Dual										
Diagnosis, Adolescen*										
Paediatric Bipolar*	0	0	0	0	0	0	0	0	0	0
Dual										
Diagnosis, Adolescen*										
Bipolar*	0	0	0	0	0	0	0	0	0	0
Substance*										
Juvenile Mania, Substance*	0	0	0	0	0	0	0	0	0	0
Juvenile Bipolar* Co	4	2	0	0	0	0	15	2	0	0
Morbid*										
Juvenile Mania, Co	3	3	0	0	0	0	3	2	0	0
Morbid*										
Juvenile Bipolar*	0	0	0	0	0	0	0	0	0	0
Dual										
Diagnosis, Juvenile										
Mania, Dual	0	0	0	0	0	0	0	0	0	0
Diagnosis,										

Juvenile Bipolar* Substance* Youth Mania, Substance* Youth Bipolar* Co morbid* Youth Mania, Co Morbid* Youth Mania, Dual Diagnosis, Youth Bipolar* Dual Diagnosis, Youth Bipolar* Substance* Teen* Mania* Substance* Teen* Paediatric Bipolar* Substance* Teen* Bipolar* Co morbid* Teen* Mania, Co	2	2	0	0	0	0	2	2	0	0
	0	0	0	0	0	0	0	0	0	0
	13	11	0	0	0	0	8	7	0	0
	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0

morbid* Teen* Paediatric Bipolar* Co morbid* Teen* Bipolar* Dual Diagnosis, Teen* Mania, Dual Diagnosis, Teen* Paediatric Bipolar, Dual Diagnosis, Teen*	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0

Appendix C Data Extraction Form

Aims of Study	
Study Design	
Study Population	
Analysis Used	
Results	
Authors Conclusions	
Comments	

Appendix D NICE Quality Checklist

		Yes or NA	Partially	No	Not Reported
Population	Is the source population or source area well described? Is the eligible population or area representative of the source population or area? Do the selected participants or areas represent the eligible population or area?				
Method of exposure/comparison group	Selection of exposure (and comparison group). How was selection bias minimised? Was the selection of explanatory variables based on a sound theoretical basis? Was the contamination acceptably low? How well were likely confounding factors identified and controlled?				
Outcomes	Is the setting applicable to the UK? Where the outcome measures and procedures reliable? Were the outcome measures complete? Was there a similar follow-up time in exposure and comparison groups? Was follow up time meaningful? Were multiple explanatory variables considered in the analyses? Were the analytical methods appropriate? Was the precision of association given or calculable? Is association meaningful?				
Summary	Are the study results internally valid? (i.e. unbiased) Are the finding generalisable to the source population (i.e. externally valid)?				

Appendix E Ratings from the Quality Checklist

	Lorberg et al. (2010)	Steinbuchel et al (2009)	Hua et al (2011)	Masi et al (2008)	Wilens et al (2014)
Is the source population or source area well described?	Yes	Yes	Yes	Yes	Yes
Is the eligible population or area representative of the source population or area?	Yes	Yes	Yes	Yes	Yes
Do the selected participants or areas represent the eligible population or area?	Yes	Yes	Yes	Yes	Yes
Selection of exposure (and comparison group). How was selection bias minimised?	Partially	Partially	Partially	Partially	Partially
Was the selection of explanatory variables based on a sound theoretical basis?	Yes	Yes	Yes	Yes	Yes
How well were likely confounding factors identified and controlled?	Partially	Partially	Partially	Partially	Partially
Is the setting applicable to the UK?	Partially	Partially	Partially	Partially	Partially
Where the outcome measures and procedures reliable?	Yes	Yes	Yes	Yes	Yes
Were the outcome measures complete?	Yes	Yes	Yes	Partially	Yes
Was there a similar follow-up time in exposure and comparison groups?	NA	NA	NA	Partially	NA
Was follow up time meaningful?	NA	NA	NA	Partially	NA
Were multiple explanatory variables considered in the analyses?	Partially	Partially	Partially	Partially	Partially

Were the analytical methods appropriate?	Yes	Yes	Yes	Yes	Yes
Was the precision of association given or calculable? Is association meaningful?	Partially	Partially	Partially	Partially	Partially
Are the study results internally valid? (i.e. unbiased)	Partially	Partially	Partially	Partially	Partially
Are the finding generalisable to the source population (i.e. externally valid)?	Partially	Partially	Partially	Partially	Partially
Percentage Quality (out of highest possible score)	75%	75%	75%	78%	75%

	Wilens et al (2009)	Goldstein et al (2013)	Goldstein et al (2008)	Stephens et al (2014)	Kenneson et al (2013)	Wilens et al (2013)
Is the source population or source area well described?	Yes	Yes	Yes	Yes	Yes	Yes
Is the eligible population or area representative of the source population or area?	Yes	Yes	Yes	Yes	Yes	Yes
Do the selected participants or areas represent the eligible population or area?	Yes	Yes	Yes	Yes	Yes	Yes
Selection of exposure (and comparison group). How was selection bias minimised?	Partially	Partially	Partially	Partially	Partially	Partially
Was the selection of explanatory variables based on a sound theoretical basis?	Yes	Yes	Yes	Yes	Yes	Yes
How well were likely confounding factors identified and controlled?	Partially	Partially	Partially	Partially	Partially	Partially
Is the setting applicable to the UK?	Partially	Partially	Partially	Partially	Partially	Partially
Where the outcome measures and procedures reliable?	Yes	Yes	Yes	Yes	Yes	Yes
Were the outcome measures complete?	Yes	Partially	Yes	partially	Partially	Yes
Was there a similar follow-up time in exposure and comparison groups?	NA	Partially	NA	NA	NA	NA
Was follow up time meaningful?	NA	Partially	NA	Yes	Yes	NA
Were multiple explanatory variables considered in the analyses?	Partially	Partially	Partially	Partially	Partially	Partially
Were the analytical methods appropriate?	Yes	Yes	Yes	Yes	Yes	Yes
Was the precision of association given or calculable? Is association	Partially	Partially	Partially	Partially	Partially	Partially

meaningful?						
Are the study results internally valid? (i.e. unbiased)	Partially	Partially	Partially	Partially	Partially	Partially
Are the finding generalisable to the source population (i.e. externally valid)?	Partially	Partially	Partially	Partially	Partially	Partially
Score (out of a possible 32)	75%	78%	75%	78%	78%	75%

Appendix F Submission Guidelines for the journal of Psychology and Psychotherapy

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Title page is page 1. On the first page, type the running head (short title for top of each page), title (which cannot include any acronyms), names of the authors and their academic degrees, grants or other financial supporters of the study, address for correspondence and reprint requests, and corresponding author's telephone and fax numbers and e-mail address.

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Acknowledgement

This section includes acknowledgment of people, grant details, funds, etc.

Note: If an author fails to submit his/her work as per the above instructions, they are requested to maintain clear titles namely headings, subheading.

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These should be used at a minimum and designed as simple as possible. We strongly encourage authors to submit tables as .doc format. Tables are to be typed double-spaced throughout, including headings and footnotes. Each table should be on a separate page, numbered consecutively in Arabic numerals and supplied with a heading and a legend. Tables should be self-explanatory without reference to the text. Preferably, the details of the methods used in the experiments should be described in the legend instead of the text. The same data should not be presented in both table and graph form or repeated in the text. Cells can be copied from an Excel spreadsheet and pasted into a word document, but Excel files should not be embedded as objects.

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Appendix G Interview Schedule

The Experience of Mania in Young Adults with Bipolar Disorder – Interview Schedule

*Prior to the interview taking place, the interviewer will discuss with the participant the use of the term mania in the interview schedule and whether the participant would like to use a term more appropriate to their experience, e.g.: “getting” or “going high”.

- **What are your views on mental health?**

Prompt – what do you know about mental health?

- **Did you have any views about people with mania before you experienced a manic episode?**

Prompts – Did you know anything about mania? Had you seen anyone else experience these things?

- **Could you tell me about the first time you experienced mania?**

Prompts – What happened? What were you doing around the time the mania occurred ?

- **How would you describe yourself following your manic episode?**

Prompts – How do you feel about yourself?

- **Do you think the experience has had an impact on you, if so how?**

Prompt – How did you see yourself before your manic episode?

- **Is life now different for you, if so in what ways?**

Prompt – are there anything you did that you don’t do anymore, are there things you now do?

- **How do you think other people view you?**

Prompt – family, friends, boyfriends/girlfriends, work, education

- **Do you think that has changed since you experienced mania?**

Prompt – what was different before?

- **Could you tell me how you feel about experiencing mania?**

Prompt – what if it happened again? Did you get anything from the experience?

- **Can you tell me about how you feel about Bipolar?**

Prompt – what do you think about Bipolar? How does Bipolar relate to you?

- **Could you tell me how you see your future?**

Prompt – What would you like to do in the future? Do you see mania as part of your future?

Appendix H Research Ethics Committee Approval



Health Research Authority

NRES Committee West Midlands - Solihull

East Midlands REC Centre
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Tel: 0115 8839440
Fax: 0115 8839294

28 December 2012

Miss Katie Turner
Trainee Clinical Psychologist
2gether Trust
Clinical Psychology Doctorate
James Starley Building, Priory Street
Coventry
CV1 5FB

Dear Miss Turner

Study title: Investigating the Experience of Mania as a Significant Life Event in Young Adults with Bipolar Disorder.
REC reference: 12/WM/0315
Amendment number: 1
Amendment date: 07 December 2012
IRAS project ID: 95033

The above amendment was reviewed at the meeting of the Sub-Committee held on 21 December 2012.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)	1	07 December 2012

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

A Research Ethics Committee established by the Health Research Authority

Statement of compliance


The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

12/WM/0315:

Please quote this number on all correspondence

Yours sincerely



RP

Dr Rex J Polson
Chair

E-mail: nrescommittee.westmidlands-solihull@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Dr Kelly Spencer, Coventry & Warwickshire Mental Health Partnership Trust*
Prof Ian Marshall

Appendix I Participant Information Sheet

Information for Participants

Project title: The Experience of Mania in Young Adults with Bipolar Disorder

This study is part of a Doctorate in Clinical Psychology. Please take time to read the following. Should you then be interested in participating in the study, please let your key worker know at the end of your discussion about the project. Your key worker will then contact the chief investigator who will be able to arrange a suitable date and location for you to attend an interview. Participation in this study is entirely voluntary.

Why have I been asked to take part?

Young people (aged between 18-25) who have experienced mania and have been diagnosed with Bipolar Disorder in the past 12 months in the Coventry and Warwickshire area have been contacted via their key workers to request their participation in the study.

What is the study's purpose?

This study aims to explore young people's first experience of mania and the impact this may have had on their attitudes and views about themselves and others. There is a lot a research which focuses on the biological aspects of Bipolar Disorder and Mania, but there has been little attention shown so far to the people who experience Mania, and even less on young adults' views about their experiences. It is hoped that this research may give others a better understanding of what it is like to be a young adult who has experienced a manic episode, as well as providing an opportunity for people to discuss those experiences.

What would I have to do?

If you choose to participate, the chief investigator will meet with you, at a place where you feel safe such as a room in the Early Intervention Centre. You will be able to invite your key worker or another person who supports you along to the interview, although they do not have to be in the interview room with you. A convenient time to conduct the interview would be arranged with you. It is expected that the interview would last approximately an hour and a half. It will be digitally recorded. The interview will ask you about your experience of mania.

Prior to the interview the chief investigator will introduce herself and go through this consent information with you again. In addition to the interview you will be asked to sign a consent form.

It is expected that you will be involved in the study for approximately two hours.

What will happen to my interview?

Once completed, your interview recording will be transcribed and then analysed along with other participant interviews. Some interview quotes may be used in the final report for the study but they will be made anonymous and the research team will make sure participants are not personally identifiable from any quotes used. After the interviews have been transcribed the digital recordings will be destroyed.

What will happen to the results of this study?

It is hoped that findings of the study will be published in a peer reviewed journal. A final report will be submitted to Coventry University as part of the chief investigator's doctorate course and a summary of the findings can be sent to you, if you wish.

Confidentiality and anonymity:

All data will be kept confidential and used for the sole purpose of the current study. All participants will be assigned a participant code which all information they provide will be identified by.

Although the chief investigator will not ask questions of a sensitive nature, it might be that some of your answers involve the disclosure of sensitive information. This will be kept confidential unless the chief investigator believes this details a current risk to yourself or others safety. **In this case confidentiality will be broken.** In such an event, chief investigator will always try to discuss their concerns with you before breaking confidentiality.

The chief investigator will only share your interview once they have made it anonymous, at which point it is likely to be shared with the other researchers in the team (those named on this information sheet) and parts with a peer supervision group to ensure reliability of analysis. All data will be made anonymous promptly after its collection.

How will my data be stored?

All data will be stored in locked cabinets at secure Coventry University or NHS sites. Any electronic data will be kept on encrypted memory devices and also kept in locked cabinets at these sites.

Once the study is complete, your name and contact details will be destroyed and interview recordings will be deleted as soon as they are transcribed. Anonymous data which will include interview transcripts will be kept securely at Coventry University for 5 years after which it will be destroyed.

What if I change my mind and no longer want to participate in the study?

Participation in this study is entirely voluntary and if you choose not to participate it will not impact on your treatment in any way. If you choose to withdraw your consent, you can do without having to provide your reason by contacting the chief investigator. You can withdraw your data from the study any time up to a month after the date of your interview.

Are there any potential risks to participating in the study?

As with most research, it is possible that participation may raise issues which you may find difficult or emotive. Following the interview, you will have the opportunity to reflect on the interviews and raise any queries if you should have them. Should this be the case, interviews can be terminated, immediate support given and information provided about further support services you may wish to access.

If you would like to discuss issues around taking part in research with an independent advisor, or to raise any concerns or comments, you can contact the Patient Advice and Liaison Service (PALS).

Their address is Wayside House, Wilsons Lane, Coventry, CV6 6NY. Their telephone number is 024 7653 6804 or you can email them at pals@covwarkpt.nhs.uk.

Is there anymore Support?

If you find, after the interview has taken place, that there were issues raised which made you feel distressed, uncomfortable or wanted to consider the points more, there are a number of places you can seek support. Your key worker will be aware of your involvement in the research so you could talk to them. You could also contact PALS at the address above.

There are a number of help lines available for people who are experiencing distress that could also offer support to you. Examples of these are Rethink Mental Illness Tel: 0300 5000 927, Samaritans Tel: 08457 90 90 90 and Mind Tel: 0300 123 3393.

Who is the research team/who can I contact?

1. Chief Investigator: Katie Turner, Trainee Clinical Psychologist. Clinical Psychology Doctorate. Coventry University, James Starley Building, Coventry, CV1 5FB. Tel: 02476 887806. Email: turnerk6@uni.coventry.ac.uk

2. Research Supervisor: Dr. Eve Knight, Clinical Director, Clinical Psychology Doctorate. Coventry University, James Starley Building, Coventry, CV1 5FB. Tel: 02476 887806.

3. Research Supervisor: Dr. Adrian Neal, Principal Clinical Psychologist, Jepson House, 2 Manor Court Avenue, Nuneaton, Warwickshire, Tel: 02476321504,

4. Research Supervisor: Dr. Dominic Martin, Principal Clinical Psychologist, St Michaels' Hospital, St Michael's Road, Warwick, CV34 5QW, Tel: 01926406714

Appendix J Participant Consent Sheet

Project title: The Experience of Mania in Young Adults with Bipolar Disorder

Please read the points below and initial each box to indicate that you understand and agree to each point before signing and dating at the bottom of the page.

I confirm that I have read and understood the Participant Information Sheet for the above study and have been given the opportunity to ask any questions or raise any issues with the researcher.

☐

I agree to participate in the above study.

☐

I give permission for my interview to be digitally recorded, transcribed and used anonymously for the purposes of research.

☐

I give permission for the chief investigator to share my anonymous data with the wider research team as identified on the participant information sheet and a peer supervision group for analysis purposes.

☐

I understand the following:

That all my data with the exception of personally identifiable data, contact details and interview recordings will be stored securely for the duration of the study and kept for a further 5 years securely at Coventry University, after which it will be destroyed. Personal and contact details will be destroyed as soon as analysis is complete.

☐

That all information will be treated as confidential with the sole exception of circumstances where the researchers have concerned for either my or others' safety.

☐

That all information will be treated as anonymous. I will not be identifiable from any findings published or to anyone other than the chief investigator with the sole exception of the above point.

☐

That my participation is voluntary and I can withdraw my consent at any time up to one month after being interviewed..

☐

Signed: Date.....

Participant name:

Participant signature.....

Researcher's name: Katie Turner, Researcher's signature:

Appendix K Excerpt of Participant Transcript with Initial IPA Coding

43 Yeah I suppose I think sorry that was a really long winded way of
44 telling you I think I was probably about 18 when it first but the
45 diagnosis was December time probably about 18 months ago

46 And that was because of the rapid cycling?

47 Yeah cos that September was when the suicide attempts happened
48 and then erm I was made to do a mood dairy and that's when like a
49 lot of referrals came up they came up with bipolar my the clinical
50 psychologist is really erm cautious about giving a diagnosis and for a
51 long time and because we have also got a history of suicide in our
52 family he said that's another strong genetic thing that led to the
53 diagnosis as well cos my brother killed himself my grandfather and
54 my great-aunt so we've got quite a history of suicide which is linked
55 to bipolar as well so it's quite interesting

56 Focus of research is the first manic episode, so what was the first
57 episode you noticed?

58 That's quite hard, I know the first manic episode that I now know
59 was a manic episode cos as a child I was very quiet and studious and
60 quite shy and it kind of like after my brother died he was very
61 outgoing and I think he had bipolar as well and after he died and
62 that trauma it like triggered I got very I was suddenly really extrovert

63 really life and soul of the party just completely extreme and I went

64 on holiday with some friends of mine and my friends mum and step

65 dad and a friend and another friend and I was just completely a

66 different person but no one worried because id been under

67 depression for so long and I suddenly it was like I was a completely

68 different person really reckless and insensitive and dangerous and

69 completely extreme but no one worried about it cos they were just

70 like well she's doing what 18 year olds do she's having the time of

71 her life but looking back I realised I was just completely I was doing

72 all the typical like spending too much money and promiscuity and I

73 found a stray dog and brought it home to the hotel to my friends

74 because I thought she'd like it cos she got upset cos we were going

75 out all the time I was just getting off with different men very risky

76 behaviour that you just wouldn't do and I didn't know anyone cos

77 we were in xante getting off with all these different people like

78 completely out of character cos I hadn't been like that at all before

79 and yeah one time is stole this dog and brought it back into the

80 hotel room at three in the morning and my friend was just like what

81 are you doing but I think people in a sense were relieved cos they

82 thought oh she's looks like she's having the time of her life so I think

83 that was the first manic episode but erm its interesting with me cos I

84 don't get psychosis when I'm manic I get it when I'm depressed so I

*became great fun
while manic*

*total change in personality
when manic*

*mania was attributed
to being hormonal 18
behaviour - even
though not how she
was*

Holly ②

Stage 1

Long time between 1st onset + diagnosis / delayed diagnosis due to lack of acknowledgement of mania?

made to do a mood diary as part of diagnostic procedure

her history of suicide in family is indicator of bipolar / family history as understanding / informing diagnosis

Only aware of 1st episode of mania in retrospect.

as a child very quiet + studious + shy, family links with bipolar - 1st degree relative
brother during teenage! extrovert behaviour

mania = extrovert, life + soul of the party, completely extreme

while manic went on holidays with friends and was a different person / completely different person
anything mania as more socially desirable than depression / repeated for emphasis

mania = really reckless, insensitive dangerous completely extreme

having the time of her life = from outside mania can look very enjoyable
manic behaviour compared attributed to normal teen behaviour

Looking back she thinks she was doing typically manic things

completely out of character cos I hadn't been like that before

bad parts of mania = spending promiscuity, odd behaviour risky (shame) (embarrassment)

reputation of getting off/promiscuity = risky sexual behaviour out of character

contradictory/ambivalent = friends questioning her vs friends being relieved she isn't depressed
friend was like what are you doing but I think people in a sense were relieved

doesn't get psychosis when manic, gets it when depressed

Stage 2.

genetic

history of suicide in family

genetic predisposition

Retrospective ^{identification} ~~view~~ of mania behaviour
→ not visible while happening

Brother had bipolar

Trauma triggered mania

Life + Soul of Party

Extreme

~~Change to Self - different person~~
became someone else

Completely different person

mania is reckless/dangerous

Changes of personality preferable to depression

mania is risk

out of character

Mania behaviour viewed as positive by others

Time of her life - others view

Appendix L Super ordinate and Sub Ordinate themes for one participant

1, All about the depression

- Mania is just me
- Bipolar is for life

2. Bipolar makes me special

- Special disorder
- Mania is exciting

3. Is it me or the mania?

- Symptoms or personality?
- What is attractive about me?

4. Generations of Bipolar

- I'm the black sheep
- Have I passed it on to her?

Appendix M Addendum to Reflections

On Being a Pregnant Researcher

During the interview and analysis process I was pregnant with my longed for first child. As there were no visible signs of pregnancy at this point, I doubt it was noticeable to my interviewees, but, I was very much consumed with thoughts of my tiny pinprick of a secret and its precarious grasp on permanence. These thoughts couldn't be shared with anyone, the magical thinking that accompanies pregnancy with all the concerns about jinxes and being 'too early' prevented that, so all my fantasies and desires were concentrated and kept within me. I think this, as much if not more, than being a trainee clinical psychologist, influenced my position as a researcher. However, I didn't realise this until long after the fact.

I made the decision after my maternity leave had ended, to reanalyse my interview data. This was to be done to address concerns raised about my initial analysis, but also as a way to reconnect and re-immersify myself in the data. I began to notice things about the process of IPA and themes emerging from the data that I had just not been aware of in my first analysis. Many of these were the feelings that the interviewees were conveying to me, through the tone of their voice, their body postures, as well as the actual verbal content of their interviews. I found myself tearing up, becoming low, wanting to avoid what came next, and feeling optimistic and doubtful. These responses to the interviewee's statements and the analysis which resulted from this were very different to my first IPA attempt.

In order to understand these differences, I began to reflect upon what was different about me, how my position had shifted in-between these two analyses. The most obvious of these was that I had gone from a woman in the early stages of a first pregnancy to being a Mother. There has been quite a lot of research about how pregnancy affects the therapeutic relationship, much of it focusing on the potential effects on the client, and the transference reactions one might notice (Beinen, 1990, Guy, Guy and Liaboe, 1986). These transference reactions were certainly present through my clinical placements as my pregnancy continued which, depending on the client, enhanced or hindered the therapeutic process. I feel that these issues were also present during the research process, but rather than being mindful of the transference reactions of the interviewee, I was defending myself against the emotional aspects of the interviews. While this was an unconscious protective act, it also prevented me from really connecting and hearing what my interviewees were saying to me.

This has helped me to recognise just how important the position of the researcher is in IPA methodology. I am certainly not suggesting that pregnant women should not do research, but rather highlighting all those things that go unsaid but may influence the way one approaches their research. While this is not a new concept when writing about IPA, I know that one of the things that I have learnt from this process is to really take the time and space to understand myself, through supervision, therapy and reflection before ever assuming my ability to be able to do that with someone else.

References

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Guy, J.D., Guy, M. P., Liaboe, G.P. (1986). First pregnancy: Therapeutic issues for both female and male psychotherapists. *Psychotherapy: Theory, Research, Practice, Training*, 23(2), 297-302.