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Doctoral Thesis

Psychiatric diagnosis: Views of service users and professionals

Roisin Turner

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Statement of Word Count

Section	Main Text	Appendices (including references, tables and figures)	Total
Thesis Abstract	297	-	297
Literature Review	7,889	4,357	12,246
Research Paper	7,995	22,478	30,473
Critical review	3,774	482	4,256
Ethics Section	4,462	2,814	7,276
Total	24,417	30,131	54,548

Thesis Abstract

This thesis explores services users' and General Practitioners' (GPs') views regarding psychiatric diagnosis. These have been written within a literature review and research paper, and I have shared my own views regarding diagnosis within the critical review. The importance of sharing and hearing narratives have been highlighted throughout all three papers.

The aim of the literature review was to synthesise the qualitative findings of studies which explored GPs' views of psychiatric diagnoses and the barriers they face in supporting clients with a diagnosis. This resulted in five overarching themes being identified: Reluctance to use the medical model; The language of diagnosis; Powerlessness; Threats to a GP's role; and Difficulties negotiating and accessing support. The findings highlighted the reluctance of GPs to use psychiatric diagnosis, and how increased support from other services would assist them in their role.

The aim of the research paper was to conduct an in-depth exploration of service users' narratives regarding their journey to and following receiving a diagnosis of bipolar disorder. Twelve individuals were interviewed and a narrative approach was used to analyse the interview data. The findings are presented as a shared story and involve five phases: Life before diagnosis; The journey to diagnosis; Receiving a diagnosis; Since diagnosis; and The future. The findings highlighted that participants found receiving a diagnosis brought them relief due to acknowledgement of their difficulties, but created additional challenges for them.

Finally, the critical review discussed my reflections on my own stance of psychiatric diagnosis and how this has changed and been challenged over

the course of the study. This is presented in four sections: Reflections upon my own stance of psychiatric diagnosis; Privileged position and power; Narrative approaches; and Future practice and research. This paper is based on the reflections I made throughout the research process.

Acknowledgements

Firstly I would like to thank the 12 inspirational individuals who shared their personal stories with me. It was a priviledge to hear such emotional and powerful narratives, and I was touched emotionally by each one. I would like to thank my thesis supervisors for their support and flexibility with their time; their guidance has also been invaluable. I would like to thank my clinical tutor and placement supervisor for their support particularly when times have been stressful. My fellow trainees have been a great source of support throughout the three years and provided many positive distractions with sounds of laughter and music over the last few months.

I would like to thank my family and friends who have been so supportive and understanding. In particular my parents who have always believed in me. And finally to my fiancé who has been a rock throughout this time, you have gifted me with so much laughter, motivational words and your love and support. My words cannot express how much you mean to me and how much you have kept me going; thank you.

Declaration

This thesis represents research undertaken for the Lancaster University Doctorate in Clinical Psychology from May 2014 to May 2015. I confirm that the work presented in this thesis is my own except where otherwise referenced and acknowledged. The work has not been submitted for any other academic award.

Signed: ……………………………………………

Date: ………………………………………………

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Section One: Literature Review

Psychiatric diagnosis: A meta-synthesis of UK General Practitioners' views and barriers to care

Roisin Turner

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

All correspondence should be sent to:
Roisin Turner
Doctorate in Clinical Psychology
Lancaster University
Lancaster
LA1 4YG
Tel: 01254 592754
Email: r.turner3@lancaster.ac.uk

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[1] See Appendix A for author guidelines

Abstract

Objectives The aim of this meta-synthesis is to gain a deeper understanding of how General Practitioners' views of psychiatric diagnoses and the barriers they face in supporting clients with a diagnosis. Recommendations were made regarding management based on these findings for primary and secondary care services.

Methods A systematic search of five electronic databases (CINAHL, EMBASE, Medline, psycINFO, and Web of Science) was undertaken. The full-text search terms included General Practitioner, diagnosis, views, qualitative and United Kingdom. Twelve qualitative journal papers met the inclusion criteria and were analysed within the qualitative meta-synthesis using Sandelowski and Barroso's (2007) approach of analysis.

Results Five themes were identified: (i) Reluctance to use the medical model; (ii) The language of diagnosis; (iii) Powerlessness; (iv) Threats to a GP's role; and (v) Difficulties negotiating and accessing support.

Conclusions Findings highlight the reluctance of GPs to use psychiatric diagnosis, preferring to use an individual approach with service users instead. GPs would benefit from increased support from mental health services and other agencies, including the clinical psychology profession.

Practitioner Points The implications of the results are discussed in terms of clinical practice and future research, and include:

- Clinical psychologists to strengthen their relationship with GPs, for example, through offering supervision and advice regarding more complex clients.

- Setting up links between GPs and local services, charity organisations and self-help groups would be invaluable for clients.
- Offering support to people in disclosing emotional distress from both individual practitioners and through public mental health campaigns.

Limitations

- Half the studies focused on a diagnosis of depression which may have biased the data towards GP's views of depression.
- The majority of the selected studies did not publish the author's own position regarding the research.

Psychiatric diagnosis: A meta-synthesis of UK General Practitioners' views and barriers to care

Mental health plays an important role in every individual's daily life and mental health difficulties can impact greatly both on the individual, families and society. The number of people in the United Kingdom (UK) who experience mental health difficulties is estimated as one in four (Singleton, Bumpstead, O'Brien, Lee & Meltze, 2001). More recently it has been established that 17.6% of adults in England have at least one common mental health diagnosis, for example anxiety or depression, and a similar proportion have symptoms which do not fulfil full diagnostic criteria for common mental health diagnoses (McManus, Meltzer, Brugha, Bebbington, & Jenkins, 2009). The impact of mental health difficulties can be widespread and are linked to deprivation, low income, unemployment, poor education, poorer physical health and increased health-risk behaviour (Centre for Mental Health, 2010). Mental health difficulties have not only a human and social cost, but also an economic one, with wider costs in England estimated at £105 billion a year, including costs of medical or social care and loss in production output (Centre for Mental Health, 2010).

The Centre for Economic Performance's Mental Health Policy Group (2012) stated that approximately a quarter of all service user[2] visits to their General Practitioner (GP) are regarding mental health issues. This number however is likely to under represent the true level

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[2] The terms service user and client have been used within this paper as opposed to 'patient' according to the Division of Clinical Psychology (DCP, 2015) guidelines regarding diagnostic language. Exceptions to this are when the word 'patient' is used within a quote.

of contact with GPs for mental health related difficulties as some service users may present with physical symptoms in the first instance (Kessler, Lloyd, Lewis, & Gray, 1999). The Joint Commissioning Panel for Mental Health (2012) produced guidance for commissioners of primary mental health care services. It stated that principally the primary care team, of which the GP is usually a service user's first contact point, should manage mental health problems through collaborative working with other services, access to specialist expertise and access to a range of secondary care services as required. As gatekeepers for referral to specialist care this often involves making mental health referrals (The King's Fund, 2010). About a third of people with serious and enduring mental illness are managed solely by GPs in primary care (Reilly et al., 2012). GPs are often faced with a range of service user difficulties, the most common being anxiety and depression (Demyttenaere et al., 2004). Agyapong, Jabbar and Conway (2012) surveyed GPs in Ireland and found that although they felt more comfortable in managing service users with a diagnosis of depression or anxiety, GPs felt less comfortable managing those who had been given diagnoses of personality disorder, bipolar disorder or schizophrenia. It has been recommended that mental health training should be a key component of GP training as the majority do not spend time within mental health placements (Centre for Economic Performance's Mental Health Policy Group, 2012).

Psychiatric diagnosis is currently a contentious topic, and clinical psychologists in particular have voiced their opinions about re-thinking diagnosis and searching for alternatives (for example, The Division of Clinical Psychology, 2013). The credibility and validity of psychiatric diagnoses, particularly schizophrenia, has been criticised in recent years (Bentall, 2003). Research has found strong associations between ethnicity, gender, social class, sexual abuse and many forms of distress (Johnstone, 2000; Rogers & Pilgrim, 2003; Tew, 2005), which suggests that taking into account an individual's social context is fundamental.

Psychiatric diagnosis is the main route into specialist care and intervention. Clinical guidelines for mental health such as National Institute for Health and Care Excellence (NICE) are based upon psychiatric disorder classifications. The stepped care model (National Collaborating Centre for Mental Health, 2004) based on NICE guidelines identifies the treatment options for primary care teams for depression as watchful waiting, guided self-help, computerized cognitive-behavioural therapy (CBT), exercise and brief psychological intervention for those who experience mild depression. For moderate and severe depression the model advises medication, psychological interventions and social support. The guidance suggests that service users deemed with more complex needs are referred to mental health specialists. It is reported that there are a number of reasons why GPs often choose not to refer service users, for example, not having time to make a referral, a lack of services to refer into and difficulties accessing services (Telford, Hutchinson, Jones, Rix, & Howe, 2002). GP's views of diagnosis may also be an influence on their choice of referral and treatment. For example in terms of depression, GPs have expressed resistance to the medical model approach of viewing depression, which they considered to be a reductionist approach (Stange & Ferrer, 2009). This may explain why GPs can be reluctant to offer or persuade service users to take medication for a diagnosis of depression (Karasz et al, 2012).

Although GPs can diagnose less complex mental health difficulties, they increasingly avoid using diagnostic labels (Rait et al., 2009). Moscrop (2012), a UK GP, has written a review regarding GP's roles in the diagnosis and treatment of depression, and pushed for seeking alternatives to diagnosis. He stated that a 'patient-centred' approach understanding an individual's problems should be used "before any consideration of symptom-scoring, diagnosing, or discussions about medications" (p. 657). A 'patient-centered' approach according to Mead & Bower (2000) incorporates five elements: a bio-psychosocial perspective; seeing the service user as a person; sharing power and responsibility; the development of a therapeutic relationship; and acknowledging the influence and subjectivity of the doctor within that relationship. The interpersonal relationship a service user has with their GP is paramount as this mutual investment can be therapeutic for service users (Little et al., 2001; Mead & Bower, 2000). Good communication was the main determinant in overall satisfaction of service user experience in primary care (Paddison et al., 2013). GPs identify their role as a holding relationship for their service users; containing, listening, monitoring and understanding being integral parts of this (Cocksedge, Greenfield, Nugent & Chew-Graham, 2011). Cocksedge et al also stated that both service users and GPs valued the shared narrative and knowledge of a service user's life-story. GPs look at the 'bigger picture' of a service user's difficulties and describe the narrative complexity of their problems (Davidsen & Reventlow, 2011).

Present study

This paper will focus on UK GPs' views towards psychiatric diagnosis and the perceived barriers faced in caring for those with mental health difficulties. The decision to focus on GPs as opposed to other professional groups was taken because GPs are often the first professionals that an individual will see regarding their difficulty, and thus are frequently the main gate-keepers to decisions regarding intervention and appropriate service referral. A number of individual qualitative studies have been conducted which explore these aspects which are of value. Qualitative research allows for a complex and rich understanding of peoples' experiences (Braun & Clarke, 2006). Research that attempts to synthesise the findings are essential to strengthen the generalisation of the findings and reach "higher analytic goals" (Sandelowski, Docherty, & Emden, 1997, p. 367). A meta-synthesis capturing GP's views within the UK has not been conducted, and this meta-synthesis aims to produce robust findings that can be used to make recommendations for future practice.

Method

The metasynthesis was completed in accordance with Sandelowski and Barroso's (2007) guidelines for synthesising qualitative literature. This approach seeks to retain the essence and unique contribution of each study, whilst producing an interpretative analysis of overarching themes in the papers.

Inclusion and Exclusion Criteria

For inclusion in the meta-synthesis all studies had to meet the following criteria: to have used a qualitative approach and used GP participant views of any psychiatric diagnosis as their main data source so that views regarding mental health and diagnosis more generally could be captured; studies conducted in the UK; studies published in English (unfortunately there was no resources to fund translators for those papers not written in English); studies published between 1995-2015 to make the scope more manageable and to ensure findings were more likely to be reflective of current practice; and papers published in a peer-reviewed journal.

The following exclusion criteria also applied: studies which included other professional groups and did not differentiate which findings were pertinent to the GP participants; qualitative studies that did not use quotations to put the data into context and evidence interpretations; studies that did not develop identifiable themes from the participants reported experiences; studies that focused on a specific area such as a mental health intervention which then limited the focus on views of mental health; and papers which reviewed other studies rather than reporting their own findings.

Data Search

Papers were identified by searching "CINAHL", "EMBASE", "Medline", "psycINFO", and "Web of Science" electronic databases in February 2015. The full-text search terms used were [General Practitioner OR General Practice doctor OR GP OR doctor] AND [mental OR diagnosis OR well-being OR stress OR psychiatr* OR illness* OR DSM] AND [views OR attitudes OR perceptions] AND [experience OR qualitative OR interviews OR grounded theory OR phenomenolog* OR narrative OR thematic analysis] AND [United Kingdom OR Great Britain OR England OR Northern Ireland OR Scotland OR Wales]. These searches resulted in the identification of 2277 papers (CINAHL = 95; EMBASE = 976; Medline = 203; PsycINFO = 689; Web of Science = 314). Subsequently all duplicates were removed and the inclusion and exclusion criteria applied to the abstracts, which resulted in 73 potential papers. If it was not clear whether they met the inclusion or exclusion criteria, the full paper was read to determine this. The author noted the reasons for each of the papers not included and this information is provided in Figure 1.

<Insert Figure 1 here>

The full texts of these 73 papers were then read and checked against the exclusion criteria which resulted in 10 studies being identified. Each of the 10 paper's reference sections were read to check if other papers had been listed that were potentially relevant. This led to another two eligible papers being identified; 12 papers in all were identified for the meta-synthesis (see Table 1).

<Insert Table 1 here>

Characteristics of Studies

Of the 12 selected papers, 11 used samples from GP clinics based in England, and one from Scotland. Sample sizes for the 12 studies ranged from 7–39 and eight studies recorded the sample gender split (56% female; 44% male across these studies). All of the papers used some form of analysis of themes for their results; seven used grounded theory, four thematic analysis, and one cognitive mapping which is an inductive approach comprising of a diagram representing the interview data. These varied approaches in analysis are founded in different epistemological stances i.e. realism, phenomenological, or constructionism. This potentially could raise issues given the different stances as the researchers' own position may influence the data they felt was valuable, and most of the studies were not transparent about the epistemological assumptions of the methods they have used. However, using a combination could also enrich the research findings (Bondas & Hall, 2007) as it may strengthen findings that are common to the studies and show that they are not purely based on the approach taken by the authors.

Quality Appraisal

Assessing the quality of qualitative research has been greatly debated and there is no definitive conclusion as to how it is done or even whether it should be done at all (Howitt, 2010). Some researchers feel that critical appraisal of qualitative research can suppress creativity (Dixon-Woods, Shaw, Agarwal, & Smith, 2004), whereas others feel that it is important to seek a balance between any methodological weaknesses and what the study adds to understanding in terms of their findings and insights (Edwards, Elwyn, Hood, & Rollnick, 2000). The current meta-synthesis assessed quality purely to determine the possible impact of study quality on the review's findings rather than as a basis for study exclusion. Appraising studies allows consideration of threats to rigour during the analysis or interpretation of the data. In addition, as the meta-synthesis can only use the available information provided in each published paper, the assessment scores indicate the quality of reporting in the research (sensitivity analysis) rather than verify the quality of the research.

The Critical Appraisal Skills Programme (CASP, 2006) was used to evaluate the strengths and weaknesses of the papers. This framework provides a transparent way of assessing quality with a range of different qualitative methods. It provides a clear definition of each criteria and includes a question regarding reflexivity, which plays an important function when conducting qualitative research (Newton, Rothlingova, Gutteridge, LeMarchand, & Raphael, 2012).

CASP identifies 10 questions considered relevant to the appraisal of qualitative research. The first two are screening questions, which ask whether there was clarity regarding the aims of the research and whether qualitative methodology was appropriate for the research aims. All 12 studies met the criteria for the screening questions. The remainder of the questions were evaluated for each study by the author (see Table 2) using a three point rating scale developed by Duggleby et al (2010): weak (1), moderate (2) or strong (3). A study that scores highly, for example, on the first question, "Was the research design appropriate to address the aims of the research", will provide valid justification for the use of their design and a clear explanation of the design. Each paper's score for the eight items are summed, and the maximum possible total score for a study is 24. CASP scores for the selected studies ranged from 14-19.

<Insert Table 2 here>

Analysis

This qualitative meta-synthesis used a process devised by Sandelowski and Barroso (2007), which guided the analysis of the findings: formulate the review question; conduct a systematic literature search; screen and select appropriate research articles; analyse and synthesise qualitative findings; maintain quality control; and present findings. They advise researchers to be systematic, comprehensive and transparent, account for and clarify all decision points, and be flexible and interpretive in their data synthesis. The findings should not simply be summaries of the primary studies' findings (see Table 3) but offer novel interpretations of the findings. In addition, because not all of the studies focused solely on GP's views of psychiatric diagnosis and how they managed service users who have been given a diagnosis, it was not appropriate to solely extract the themes the studies identified. Therefore, both direct quotes from participants' and the authors' interpretations of the participants' experiences were extracted.

<Insert Table 3 here>

To further advance the original findings from the selected studies, the author read and re-read the results and discussion sections of each paper, initially writing down the themes identified, and then other points that seemed relevant to the research question, for example, quotes, sentences and phrases. The author used post-it notes to write down these individual points, for example, within the first theme 'Reluctance to use the medical model' quotations were identified such as "I do think most of the time people do recover from it if they are just given some support rather than medication" (Chew-Graham et al., 2008, p. 172) and information such as GPs being concerned about 'medicalising' loneliness and grief (Burroughs et al., 2006; Murray et al., 2006). After doing this with all 12 studies, the author then looked across all the areas identified and pulled together common themes from the data. The use of post-it notes allowed points of information to be easily moved into related themes, and a statement summarising each main theme was constructed, using a quotation within one of the studies an example to highlight each theme. The meta-synthesis themes and the studies providing evidence within the themes are presented (see Table 4).

<Insert Table 4 here>

Within this review the author took a constructionist stance, and aimed to understand how individuals construct and reconstruct knowledge about their experiences. Schutz (1962, as cited in Reid, Sinclair, Barr, Dobbs, & Crealey, 2009) identified three levels in which a meta-synthesis' findings are constructed: a) first-order constructs which comprise of the participants' own understanding and meanings related to their experience; b) second-order constructs are those of the authors which are also influenced by their epistemological assumptions and their lived experiences; and c) third-order constructs are those of the meta-synthesis author(s) interpretations which again bring their own assumptions into the framework.

Results

Five main concepts were identified: i) Reluctance to use the medical model; ii) The language of diagnosis; iii) Powerlessness; iv) Threats to a GP's role; and v) Difficulties negotiating and accessing support. These are now described along with indicative quotes from participants in the original studies.

"Is a medical answer to this problem appropriate?": Reluctance to use the medical model

Six of the 12 papers used the diagnosis of depression as a focus for their interviews with GPs, although throughout the majority of the selected papers mental health difficulties were viewed as 'understandable' and 'justifiable'. Considering a service user's symptoms within the context of an individual's particular life was perceived as important (Burroughs et al., 2006). Depression was viewed as the result of wider social and economic problems which GPs feel powerless to alleviate (Burroughs et al., 2006). Two papers (Burroughs et al., 2006; Murray et al., 2006) focused on older service users and also found that GPs were concerned about 'medicalising' loneliness and grief in this age range:

> One of the problems being a doctor is that people come to you for a medical answer to their problems but you at the same time are having to make a judgement is a medical answer to this problem appropriate? And if you think it's not then you have to try and steer away from medicalisation of their problem. (Murray et al., 2006, p. 1367)

Chew-Graham et al's (2008) study focused on the diagnosis of post-natal depression which was perceived as a social response to birth: "I call it emotional turmoil rather than depression" (p. 171), and, "It's about normalising how they think… I think many depressions are like post natal depression actually, they exist in the context of somebody's life and it has a meaning for them which you have to attend to" (p. 172).

Burroughs et al (2006) stated that their sample of GPs suggested a move away from the biomedical model on the causation of depression and instead use a social understanding. The reluctance to ascribe a biomedical label was also found in other studies, for example, Murray et al (2006):

> If somebody's problem was that their children never visited them and they were being driven mad by the couple in the upstairs flat who played loud music day and night and they became "depressed" in inverted commas, I wouldn't want to ideally strengthen the medicalisation of their depression by referring them to an old age psychiatrist. (p. 1367)

Consequently prescribing medication was a difficulty for GPs: "It's no point stuffing people full of antidepressants when they are still left with the problem" (Chew-Graham et al., 2002, p. 635), and: "I do think most of the time people do recover from it if they are just given some support rather than medication" (Chew-Graham et al., 2008, p. 172). Shaw (2004) reinforced this view arguing that if distress is not an illness as described in the medical model, describing and treating distress in this way is unhelpful and may stimulate unrealistic expectations of treatment from the service user. GPs reluctance to prescribe medication was also explained by uncertainty regarding the effectiveness (Burroughs et al., 2006). This was based on the GPs' own experiences with service users and it appears a disillusion with the system: "What actually happens is there's a sort of general collusion or inaction, people just stay on antidepressants forever, without getting better. And don't change and nothing happens except they're on more medication and the NHS is paying for more drugs" (p. 373). The GPs in Railton et al's (2000) study also commented on clinical guidelines specifically for depression and how categorisation was often resisted: "I think psychological problems are so individual that I don't see how you can rigidly follow any guidelines or protocols" (p. 123).

"I would rather call it something else": The language of diagnosis

The terminology of diagnosis was discussed in more than half the studies, either directly or indirectly. Murray et al (2006) found that younger service users were more likely to use the 'language of stress', whereas older service users will say, "I am tired all the time, I don't have any energy" (p. 1366). Perhaps younger generations are more exposed to the medicalised language and more readily search the internet to research symptoms, therefore more aware of and automatically use the language. Murray et al (2006) also commented on ethnic and cultural differences, which the other studies did not. GPs in this study inferred that other cultures did not recognise the Westernised language of diagnosis and all but one of their sample thought cultural differences in 'illness beliefs' were significant in service users expressing and focusing on physical problems rather than their psychological difficulties.

GPs recognised that there may be some reluctance from service users to discuss their psychosocial difficulties, and they may concentrate on physical symptoms initially meaning that the identification of and therefore a diagnosis of depression was delayed (Murray et al., 2006): "They don't want to eat, and they are losing weight and they are worried about losing weight and so am I because my first thought is obviously you've got cancer. So prove them otherwise" (p. 1366). Conversely Lester et al (2005) identified that GPs recognised that once a mental health diagnosis had been made, it was sometimes difficult to then diagnose physical health complaints:

> We were seeing this woman very regularly, and she was known to have some depression, and she presented with bowel symptoms. And when we looked back through her notes, after she died from bowel cancer, we saw we'd offered to arrange scans and investigations but none of us pushed her like we might have done if we hadn't had that depression thing there. (p. 1124)

Another GP in this study also highlighted that the focus can just be on the mental health difficulties, stating that they and others "Can have a tendency to become blinkered" (Lester et al., 2005, p. 1124). Murray et al (2006) focused their paper on older service users and found that GPs would approach the subject of depression after a few appointments: "It's dangerous to go straight for the depression line. It could be something physical" (p. 1366).

A diagnosis of depression was described as hard to 'sell' to service users, particularly older service users as GPs thought that depression carries a stigma for them (Burroughs et al., 2006) or it may cause distress (Murray et al., 2006). Some GPs reported that they did not openly discuss the diagnosis and instead used other descriptions (Burroughs et al., 2006). They reported using other terms such as 'loneliness' (Burroughs et al., 2006), or differences in 'mood' or 'energy' (Murray et al., 2006) to overcome this. Perhaps this was for fear of losing the therapeutic alliance they had built, or they felt that the stigma service users may feel might cause them to reject the diagnosis. A GP in Murray et al's (2006) study also stated that that using the word 'depression' may impact on their 'doctor-patient' relationship: "They are very very put off by the mention of it and will physically clam up and that's it and I think you may have lost that relationship and have to work hard to rebuild it" (p. 1371). Building rapport with a young person was highlighted as difficult for GPs, and finding common ground was one way round this hurdle (Roberts et al., 2013). Chew-Graham et al (2008) also provided an explanation of a perceived lack of resources which deterred them from labelling depression: "There's no one to refer to, so I would rather call it something else and manage her myself" (P. 172).

"Powerless to help the patient in any other way": **Powerlessness**

GPs expressed feelings of anxiety and uncertainty, and in particular feeling powerless with regards to how they can help service users who come to consultations with mental health difficulties. Murray et al's (2006) study focused on the diagnosis of depression in older people and the difficulties GPs face within changing social contexts: "So you have people who are, if the truth were told, starved of contact and what are you supposed to do as their doctor to change that?" (p. 1367). Chew-Graham et al's (2002) study identified that the powerlessness felt by GPs was linked to their perception that there are societal causes of depression: "When we feel powerless to help the patient in any other way, or we can see that they have no other resources to turn to, then sometimes it is easy to read into the situation a diagnosis of depression" (p. 634). Another GP in this study stated: "It makes us feel good because it feels as if we are doing something, it makes us feel good because we know that the patient wll improve if we have got the diagnosis right and they take the tablets" (p. 634). Therefore this sense of being powerless to help, which ties in with the main role of the GP of helping people, may push GPs into making a diagnosis because this alleviates some of the helplessness they feel.

Anxiety regarding a lack of specialised knowledge was also a source of powerlessness. Roberts et al (2013) summarised that their sample of GPs felt anxious and uncertain about how to continue working with a young person and this 'not knowing what to do' led to a sense of disempowerment: "I have more questions than answers" (p. 4). This was explained in that there was not a clear and definable 'disorder' in which to place a young person in. These GPs stated that they did not have specific training in working with this age group. GPs in Roberts et al's (2013) study also shared their anxiety regarding the complexity of difficulties that young people presented with, and coupled with this was uncertainty due to the implicit narratives shared between GP and service users: "You feel there are these big 'no go areas' in teenage consultations, around sex, drugs, alcohol… which loom over you like a black cloud and I'm thinking that they want to talk about it and I'm thinking that I want to talk about it but we can't talk about it" (p. 5).

Reid et al (2010) found that many of the GPs in their sample felt that they lacked the experience and expertise to recognise and manage and this affected their level of confidence: “I’m well equipped to be sympathetic and to understand about other symptoms that get presented and to be supportive. But I’m not sure that there’s anything very much that I do that actually helps move people on” (p. 6), and:

> I mean medicine is easy when you can just prescribe something and then they are better and they don’t have to come back again but difficult sometimes when you have put a lot of emotion into looking after them and sometimes they don’t seem to get anywhere. (p. 6)

Shaw (2004) also suggested that GPs who perceive service users to reject the help they offer then impacts on their professional self-image and competence: “I can understand why colleagues get very frustrated and feel they are not achieving anything and ‘What’s the point?’ Then moving the patient on” (p. 1041).

Chew-Graham et al (2002) identified in their study that there is a potential for secondary gain for both service users and GPs when giving a diagnosis. For service users they can be given a "quick fix, have something done" (p. 634); there was a sense that this was also an expectation within society more generally. The perceived secondary gains for GPs providing a diagnosis were relieving feelings of powerlessness and providing security in their work. Other anxieties that propelled feelings of powerlessness included anxiety regarding service users trying to take their own lives: “It’s always a worry isn’t it that you just completely get it wrong… that you might miss something catastrophic” (Roberts et al., 2013, p. 5). Leydon et al (2011) stated that GPs are under pressure to ‘get it right’ and are accountable for the decisions that they make. Trying to access support from other services to lessen these feelings and help clients access specialist services was difficult. Shaw (2004) found that GPs refer people onto other services and practices because they feel they cannot offer the support that the client requires; it was suggested that GPs hope someone else has the solution. Even more experienced GPs described uncertainty about their practice which linked to a lack of clarity regarding what was expected of GPs particularly when faced with a scarcity of treatment options (Roberts et al., 2013).

"You can't even scratch the surface": Threats to a GP's role

There were three main perceived threats identified by GPs which compromised their role: processes which threatened their clinical intuition, lack of time and specialist training, and perceiving service users as challenging to their role.

Clinical intuition and instinct was described by GPs as a way of alerting them to the presence of a mental health difficulty: "So I'm not saying I actively look for it, but I am hoping my antennae would tell me if there was a problem" (Chew-Graham et al., 2008, p. 171). It was suggested that clinical intuition was a fundamental facet of the interaction between service user and GP: "I have to say that what I rely on most of all is just the sort of seat of the pants feel of things and just of vibes that people give off" (Railton et al., 2000, p. 125). The use of questionnaires and scales during consultations with clients was viewed as stifling, and they prefered to use intuition and 'gut feeling'. GPs tended to use their own style of questioning: "I have my own kind of mental ways in finding out if people are depressed (Burroughs et al., 2006, p. 372). GPs also felt that the use of questionnaires could be reductionist and they feared a loss of holism. The authors suggested that this may also reduce clinical judgement and intuition which was a fear to GPs. Leydon et al (2011) implied the perceived threat of questionnaire measures may impact on GPs' professional role and identity which often features independent and self-directed judgment. One GP stated that questionnaire measures "Doesn't allow you to adjust for individual situations" (p. 120), and another said, "Like any other test, including biochemical or medical tests, there is a danger that you end up treating the result of the investigation rather than the patient themselves" (p. 120). Concerns about using a reductionist approach may also parallel with views held about psychiatric diagnosis and mental health which has been highlighted in the theme of 'reluctance to use the medical model'.

GPs talked about how practical difficulties impacted on their ability to build therapeutic interactions with their clients, decision making and on the quality of the consultation. These included lack of time, structural factors within their practice, and workload: "You've got a certain pressure of seven minutes and it isn't anything like, you can't even scratch the surface" (Reid et al., 2010, p. 7), and "I think we probably miss a lot because of the pressure of time" (Railton et al., 2000, p. 121). They viewed more traditional clinical interventions as having limited effectiveness with those clients who endured socio-economic deprivation (Chew-Graham et al., 2002). Long waiting lists for therapeutic input and service users limited financial resources to access private talking therapies have thus limited GPs management of cases to diagnosis and pharmaceutical treatments (Chew-

Graham et al., 2002). GPs voiced that they wanted further training as they thought that specific expertise was required particularly with more complex mental health difficulties, and a lack of professional supervision was highlighted as problematic: “I really do feel there is a huge need for it even if it just one phone call, it’s that ability to share the responsibility, not to dump it, but to genuinely share it” (Roberts et al., 2013, p. 4).

GPs shared their anxieties and frustrations with some service users that they saw: “They’re just so frustrating because they just don’t, they don’t see that they have a problem” (Reid et al., 2010, p. 5). Reid et al’s (2010) study asked GPs about their experiences with service users who present with eating difficulties. They felt that these clients required a lot of the GPs time and GPs described them as ‘difficult’ and ‘an awful lot of work’ due to the emotions they provoked and the amount of psychological support they required. Also noted was the frustration that can arise with this type of work and how GPs can feel drained by consultations (Chew-Graham et al., 2002). Shaw (2004) found that some GP’s described service users who were frequently admitted to psychiatric hospitals as demanding, disruptive to practice routines, manipulative of the medical system and non-compliant with treatments. Shaw suggested that these views impact in the GPs’ self-image and their therapeutic credentials: “Medication does not work, counselling has failed and psychiatry do not want to know her… she complains that I am not helping her. Frankly, I do not know what to do that can help” (p. 1038). There was however a sense of positivity amongst some GPs who saw this work as challenging and interesting (Chew-Graham et al., 2002).

"We ploughed our own lonely furrow": Difficulties negotiating and accessing support

GPs highlighted their perception of lacking specialist knowledge particularly with more complex mental health difficulties which understandably impacts on a GP's confidence: "I'm a bit out of my depth with people with schizophrenia and manic depression" (Railton et al., 2000, p. 122). Making a referral to specialist services can allieviate feelings of powerlessness and helplessness. The majority of papers however identified that GPs were frustrated by the lack of treatment availability and limited resources for their clients. Some GPs felt that their only option was therefore to prescribe medication even though their prefered option would be to offer 'talking therapies' (Chew-Graham et al., 2002; Shaw, 2004).

GPs identified uncertainty regarding how to access voluntary services and the limited referral options to secondary care: "There isn't really any further care… the mental health service won't see anyone who hasn't got severe and enduring mental health illness" (Burroughs et al., 2006, p. 374), and, "This patient has been dumped by everyone else… she has had lots of doctors. We have been trying to get psychiatry to take her over but with little success at the moment" (Shaw, 2004, p. 1040). Secondary care services are viewed by GPs as possessing the resources and time to support patients, however strict diagnostic criteria means that patients are often returned back to the care of the GP because they do not meet this criteria (Shaw et al., 2004). GPs reported that there were long waiting lists for psychology services, and this was particularly problematic when GPs have worked hard to help a client acknowledge that they do need extra support:

"If you are getting people to the point where they are actually saying 'Yeah, I want help', then it's really not acceptable to have to wait a vast length of time really" (Reid et al., 2010, p. 7). Lack of time was also a factor in terms of not making a referral because often a diagnosis and formulation was required as part of the referral. GPs talked about the difficulties accessing secondary mental health care in a crisis situation, and how this was time-consuming and stressful (Lester et al., 2005). Some disclosed that they would exaggerate their patient's symptoms if they felt they were near a point of crisis so that they would be seen. Waiting list times were also a concern, particularly at a time of crisis (Prasad et al., 1999).

When a referral is made GPs are often left feeling frustrated because they do not consistently receive communication from other services into which they direct their clients, for example, accident and emergency, Community Mental Health Teams (CMHTs), Social Services and voluntary agencies (Hinrichs et al., 2012; Prasad et al., 1999). This then can impact on the clarity of future care and treatment for the GP as they are not aware of what other services are providing and the progress of their patient: "I didn't hear back from voluntary organisation. I never hear back" (Hinrichs et al., 2012, p. 8), and, "The communications with the CMHT are poor – we are not given a treatment plan nor told what has been done for the patient" (Prasad et al., 1999, p. 722).

Prasad et al (1999) reported that GPs thought they did not have enough time to provide a counselling role for their clients, and suggested that having mental health professionals on site may be advantageous. Railton et al (2000) stated that counselling services had been developed for a number of practices within their study sample to try and alleviate this issue: “You have a limited capacity to deal with all of it” (p. 123). In Hinrichs et al’s (2012) study it was noted that in some of the GP practices there were monthly multi-disciplinary team (MDT) meetings with specialist agencies and this helped to safeguard any lack of specialist knowledge felt by the GP, and possessing constructive MDT relationships with other services signified reduced expressed anxiety (Roberts et al., 2013). Railton et al (2000) identified the key role of a support worker within their practices who had the knowledge and experience of working within mental health and offered support to the GP in terms of clinical case management: “We ploughed our own lonely furrow to some extent, so it’s really nice to have someone in the Practice who can actually give positive support and someone you can refer to and discuss problems with” (p. 123). GPs in this study also felt they needed more support in their work and often felt unsupported by psychology and psychiatry services. A GP in Roberts et al’s (2013) study stated: “Some (mental health) creatures are on the verge of being mythical beasts… like psychotherapists… educational psychologists” (p. 4). Prasad et al (1999) highlighted that the majority of their sample of GPs wanted a community psychiatric nurse (CPN), counsellor or psychologist to be attached to the surgery.

Discussion

The aim of the meta-synthesis was to advance understanding of GPs’ views regarding psychiatric diagnosis and subsequently how they support people with a diagnosis. Findings from 12 published qualitative studies which explored service users’ first-person accounts of their experiences were critically re-interpreted using a qualitative meta-synthesis process developed by Sandelowski & Barroso (2007). Five main concepts were identified from the studies, namely, reluctance to use the medical model; the language of diagnosis; powerlessness; threats to a GP's role; and difficulties negotiating and accessing support. Whilst each of these higher-order concepts were consistent with the findings of the original studies, they also extended beyond them. Consequently more comprehensive understanding has been generated which provides some insight into the challenging processes experienced by GPs trying to provide care and support for those who have mental health difficulties.

As the transcripts were analysed it became apparent that the GPs were describing a process, which is depicted within Figure 2.

<Insert Figure 2 here>

The diagram is intended to illustrate the main process and dilemmas that GPs may experience when a client with mental health difficulties attends consultation; it does not intend to demonstrate all possibilities nor determine the effectiveness of choice made by GPs. The meta-synthesis found that GPs' views of mental health difficulties were important in their decisions of how best to care and support clients. They viewed mental health difficulties often as understandable responses to life events, and their role of building a therapeutic relationship with their clients was perceived as vital to their work and clients' care. This involved listening to the client's narratives, building trust, understanding the client's perspective, offering reassurance, warmth and a message of hope (for example, Railton et al., 2000). Hearing narratives helps build understandings of difficulties, and GPs normalised experiences for patients (Davidsen & Reventlow, 2011). GPs expressed reluctance in using the medical model to diagnose and use questionnaire measures, which they felt were reductionist and did not account for individual circumstances. This is consistent with previous studies (Stange & Ferrer, 2009), and reinforces the explanation as to why GPs are reluctant to offer medication or provide diagnoses (Karasz et al, 2012). The very human element they brought to their consultations was perceived as threatened by more structured and less intuitive processes such as the use of questionnaires and protocols.

GPs were also reluctant to use diagnostic language for fear of increasing stigma, creating a negative impact on their therapeutic relationship and concerns that they may become 'blinkered', only seeing the psychiatric label and potentially missing physical problems. The use of medicalised language can encourage people to be thought of as a 'disorder' or 'illness' rather than first and foremost as a person (Dixon, 1983). Consequently GPs preferred to use their own terms or the language that their clients used, which then meant they had more influence as to whether they care for a service user themselves or to refer to another service. This is consistent with previous research which found GPs were more likely to use symptomatic labels rather than diagnostic labels (Rait et al., 2009). The GPs perceived role is one of a 'helper' whereby they provide answers and solutions can be found by taking a more narrative approach rather than using medicalised language. This can allow individual and cultural differences to be encompassed (Launer, 2003).

The feelings of powerlessness GPs felt at times appeared to link to their perceptions of their role as 'helpers', and therefore when they felt unable to fulfill this role it caused anxiety. GPs are often holding the care of patients with serious needs, which also brings anxiety, as found in Agyapong et al's (2012) study. The perceived social causes of mental health difficulties produced uncertainty of what GPs can do to help, and they were more likely to want to use their supportive role as a method of intervention rather than medication. However if this was deemed as not effective or not realistic in terms of available time, they would use diagnosis and medication as a way of allieviating further feelings of powerlessness. A perceived lack of specialist knowledge, treatment options and support from other services were also causes of feelings of powerlessness amongst GPs. The difficult path to gaining acceptance for referrals and support from other services and long waiting times for specialist services often mean that GPs managed clients themselves and obtained advice from an external agency, whereas a shorter waiting list meant they would refer straight away. These findings are in line with those found by Telford et al (2002) who found GPs are less inclined to refer clients because of a lack of services to refer into and difficulties accessing services.

Clinical Implications

The themes identified in the meta-synthesis provide several important clinical implications. The GPs reluctance to use the medical model and consequent use of psychiatric diagnosis and medication options appears to be similar to clinical psychology approaches. The new DCP guidelines (2015) in terms of psychiatric language to a degree correspond with the language GPs use, particularly as GPs appear to be aware of the possible impact of stigma upon an individual. Research has emphasised the difference in approaches between psychiatrists and GPs. For example, GPs focus on the context and wider social context of their client's symptoms, whereas psychiatrists focus on diagnosis and treatment of illness (Railton et al., 2000). GPs' understanding of depression has been shown to be more similar to service users (Rogers, May, & Oliver, 2001). The similar philosophy between GPs and clinical psychologists is an area that could be enhanced, and in particular for clinical psychologists to strengthen their relationship with GPs, for example, through offering supervision and advice regarding more complex clients. Case discussions and sharing psychological knowledge would assist GPs across cases, for example, in Shaw's (2004) study some GPs' perceived clients with more complex needs as 'manipulative', and perhaps thinking about concepts such as countertransference may enable them to understand underlying processes that may be present. The use of psychological formulation within consultations may provide GPs with a more helpful alternative to diagnosis, as proposed by Johnstone (2006). A psychological formulation provides a hypothesis about an individual's difficulties, linking theory with practice and guiding the intervention. It would enable GPs to increase their understanding of their clients's difficulties, aid them to explore their own emotions and responses to their clients (Division of Clinical Psychology, 2011) and therefore may help them feel less powerless and hopeless.

The attendance of specialised professionals at MDT meetings within primary care settings is encouraged as this would aid GPs in terms of consultation regarding complex cases, supervision, and potential training opportunities. Setting up links between GPs and local services, community and charity organisations would be invaluable. The value that communities and families bring to individual's lives was highlighted by GPs (Murray et al., 2006). The use of self-help groups would also enable services users to obtain support within their community. Burroughs et al (2006) concluded that primary care must address issues such as the provision of psychological therapies within primary care. The role of Improving Access to Psychological Therapies (IAPT) is a step towards improving access, however there is criticism due to its focus on CBT approaches that it attempts to fix a 'problem' which lies within an individual: "Most therapies aim to hear what is being expressed in a symptom: not to stifle it, but to give it a voice and see what function it has for the individual. CBT, by contrast, aims to remove symptoms" (Leader, 2008). This again is at odds with how GPs' perceive mental health difficulties, in particular depression.

Supporting people to disclose the presence of emotional distress is a challenge for health services, and this study has implications for both individual practitioners and mental health campaigns. The reluctance by service users to disclose their mental health difficulties is a concern, particularly as GPs are often the main gateway to appropriate service referral. When enquiring about emotional difficulties, GPs should seek to understand how their patients construe their mental health, as well as being alert to the effects of stigma. Public education campaigns should also consider these factors. There is now guidance that has been produced to help service users become more aware of the role of their GP within mental health, and how they can use their consultation time to meet their needs regarding mental health (Mental Health Foundation, 2014).

Limitations and Future Research

In the present review, a potential limitation is that six of the 12 papers focused on the diagnosis of depression. This may have impacted upon GPs' perceptions regarding their understanding of the causes of mental health difficulties and how they approach these difficulties. People with diagnoses of depression and anxiety are more commonly managed by GPs within primary care (Demyttenaere et al., 2004), and GPs have reported that they feel more comfortable in dealing with these types of difficulties (Agyapong et al., 2012). Therefore they may be less inclined to refer service users with these difficulties to specialist services. There was however evidence for this from the other papers which did not focus on depression. This would be a suggested area for future research to explore and compare other diagnoses, specifically those perceived as more complex for GPs to support. Another potential area for future research is to explore the relationship between GPs and clinical psychologists views, and how psychologists could support GPs in their role, particularly with more complex clients.

The CASP quality appraisal tool rated the majority of the papers used in the meta-synthesis as 'moderate' or 'strong', suggesting that they employed appropriate design and methodology and demonstrated a thorough approach to analysis and presentation of the findings. The majority of the papers however did not comment on the author's own position regarding the research and therefore how this may have impacted on the analysis and findings. The CASP tool does analyse the quality of reporting rather than the quality of the research undertaken, therefore it is difficult to comment on whether the absence of this may have impacted on the quality of the paper. It could be that the reflexivity sections of a paper are removed when submitting research for publication due to strict word limits.

Conclusion

This meta-synthesis has explored GPs' views regarding psychiatric diagnosis and how they support clients with a diagnosis. The findings suggest that GPs are sensitive to their clients needs in terms of the language used and their reluctance to diagnose clients for concerns regarding stigma. GPs would benefit from increased support in their role from mental health services and other agencies, and clinical psychologists potentially could have a significant role within this.

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Table 1. Summary information of the papers selected for the meta-synthesis

Paper	Research aim	Methodology	Available information regarding participants
Burroughs et al (2006)	To explore the ways that primary care professionals and patients view the causes and management of late-life depression	One-to-one semi-structured interview; Constant Comparison Approach (Grounded Theory)	n = 9 GPs; England
Chew-Graham et al (2008)	To explore the views of GPs and health visitors on the diagnosis and management of postnatal depression	One-to-one semi-structured interview; Thematic Analysis	n = 19 GPs; England
Chew-Graham et al (2002)	To explore GP attitudes to the management of patients with depression	One-to-one semi-structured interview; Constant Comparison Approach (Grounded Theory)	n = 22 GPs working in inner-city areas, n = 13 working in suburban and semi-rural areas; England
Hinrichs et al (2012)	To investigate GPs' perceptions and experiences in the referral of children and adolescents with mental health difficulties	One-to-one semi-structured interview; Thematic Analysis	n = 7 GPs; male = 3, female = 4; England
Lester et al (2005)	To explore the experience of providing and receiving primary care from the perspectives of primary health care professionals and patients with serious mental health difficulties	Focus groups comprising of patients, GPs and practice nurses' Thematic Analysis	n = 39 GPs; male = 25, female = 14; England
Leydon et al (2011)	To gain understanding of GPs' views of the use of severity questionnaires in the diagnosis and management of depression	One-to-one semi-structured interview; Constant Comparison Approach (Grounded Theory)	n = 34 GPs; male = 19, female = 15; Age range 31-62 years; England
Murray et al (2006)	To identify GPs' perceptions of depression in older people	One-to-one semi-structured interview; Grounded Theory	n = 18 GPs; male = 10, female = 8; Age range 31-64 years; England
Prasad et al (1999)	To assess GPs' views on managing patients following an episode of deliberate self-harm	One-to-one semi-structured interview; Grounded Theory	n = 14 GPs; male = 7, female = 7; Age range 34-63 years; England

Railton et al (2000)	To explore the experience of GPs regarding how they approached the care of patients with depression	One-to-one semi-structured interview; Constant Comparison Approach (Grounded Theory)	n = 15 GPs; male = 13, female = 2; Age range 33-56 years; Scotland
Reid et al (2010)	To explore the perceptions of GPs in diagnosing and managing the care of eating disorder patients	One-to-one semi-structured interview; Thematic Analysis	n = 20 GPs; male = 10, female = 10; England
Roberts et al (2013)	To investigate GPs' views and experiences of consulting with young people presenting with emotional distress	One-to-one semi-structured interview; Grounded Theory	n = 19 GPs; male = 9, female = 10; England
Shaw (2004)	To explore GPs' conceptualisations of frequent attending patients to GP clinics	One-to-one semi-structured interview; Cognitive Mapping Technique	n = 12 GPs; male = 10, female = 2; England

Table 2. Critical appraisal of study quality using the CASP qualitative appraisal tool

Paper	Design	Sampling	Data collection	Reflexivity and bias	Ethical issues	Data Analysis	Findings	Value of research	Total score
Burroughs et al (2006)	2	2	2	1	2	2	2	2	15
Chew-Graham et al (2008)	2	2	2	1	2	2	2	2	15
Chew-Graham et al (2002)	2	2	2	1	1	2	2	2	14
Hinrichs et al (2012)	2	2	2	1	2	2	2	2	15
Lester et al (2005)	2	2	3	1	2	2	2	3	17
Leydon et al (2011)	2	2	3	1	2	2	2	3	17
Murray et al (2006)	2	2	3	1	1	2	2	2	15
Prasad et al (1999)	2	3	3	2	1	2	2	2	17
Railton et al (2000)	2	3	2	1	1	2	2	2	15
Reid et al (2010)	2	1	2	1	2	2	2	2	14
Roberts et al (2013)	2	3	3	2	2	3	2	2	19
Shaw (2004)	2	2	2	1	2	2	2	2	15

Table 3. Original themes found within the papers selected for the meta-synthesis

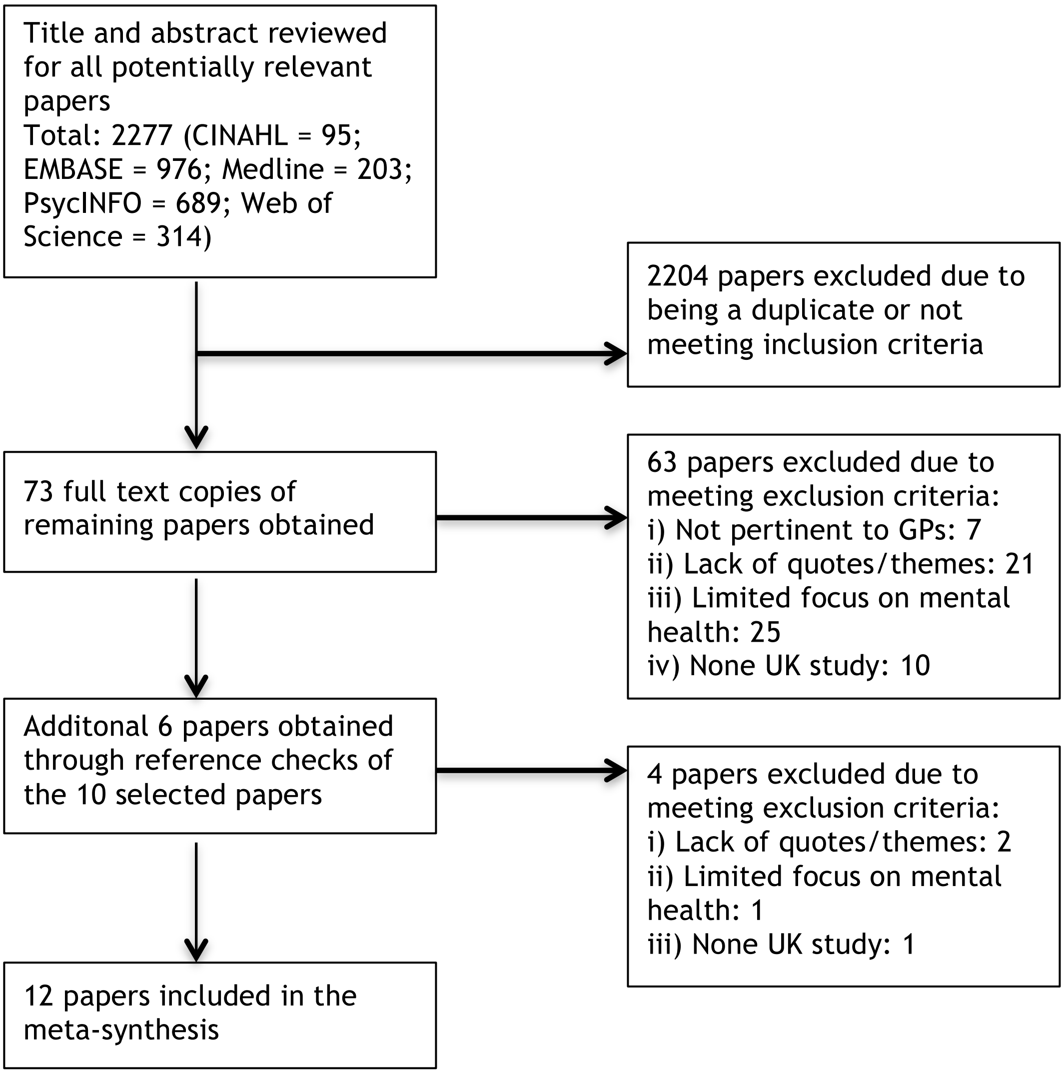
Study	Themes
Burroughs et al (2006)	Aetiology of depression Making the diagnosis Management of late-life depression in primary care Primary care relationships
Chew-Graham et al (2008)	Making the diagnosis Labelling affects management Is an established relationship important Perceptions of others' roles Ways of working Whose responsibility is the management of postnatal depression?
Chew-Graham et al (2002)	Depression as a 'normal' response to life events The potential for secondary gain? Interactional difficulties with depressed people
Hinrichs et al (2012)	Identifying mental health symptoms Choosing whether to refer Communicating with referral agencies
Lester et al (2005)	"Good enough" primary care Anticipating and negotiating access Management of chronic disease versus recovery
Leydon et al (2011)	Compromising the doctor-patient relationship Threatening holistic practice and GP intuition Deploying the severity questionnaire in the consultation interaction
Murray et al (2006)	Presenting complaints Distinguishing between depression and physical illness Depression as normal in old age Avoidance of psychosocial problems Stigma and shame Gender differences Ethic and cultural differences The family as help or hindrance
Prasad et al (1999)	Service provision for patients with deliberate self-harm Approach to management of patients with deliberate self-harm Access to community mental health teams Administrative policies for patients with deliberate self-harm Alternative models of care Guidelines Attitudes towards educational initiatives for GPs
Railton et al (2000)	Organisational issues - Appointment length - Personal lists Referral and the response of other services - Psychiatrists and GPs - Other professionals and GPs Treatment and management issues - Guidelines and protocols - Talking therapy - Drug treatment

	- Personal / professional interface - Intuition Stigma
Reid et al (2010)	Rarity of known cases in primary care - Low prevalence of eating disorders - Hard to recognise eating disorders High demands of eating disorder cases in primary care - Complex nature of eating disorders - Lack of GP experience and expertise - Holding and referral - Need for specialist services - Waiting times and scarce places
Roberts et al (2013)	Anxiety related to professional performance - Operating in the consultation - Operating at the external level - Across disciplinary boundaries Anxiety related to interacting with young people Anxiety associated with the complexity of presentations of adolescent emotional distress
Shaw (2004)	Medical irritation "Problem patients": Management Strategies Responsibility, blame and authority Toward an understanding of the revolving-door phenomenon

Table 4. Summary of key themes from papers selected for the meta-synthesis

Main themes	Paper
Mental health as an understandable response to life	Burroughs et al (2006) Chew-Graham et al (2008) Chew-Graham et al (2002) Lester et al (2005) Murray et al (2006) Shaw (2004)
The language of diagnosis	Burroughs et al (2006) Chew-Graham et al (2002) Hinrichs et al (2012) Leydon et al (2011) Railton et al (2000) Roberts et al (2013)
Powerlessness	Burroughs et al (2006) Chew-Graham et al (2002) Murray et al (2006) Reid et al (2010) Roberts et al (2013) Shaw (2004)
Threats to a GP's role	Burroughs et al (2006) Chew-Graham et al (2008) Chew-Graham et al (2002) Lester et al (2005) Leydon et al (2011) Murray et al (2006) Prasad et al (1999) Railton et al (2000) Reid et al (2010) Shaw (2004)
Difficulties negotiating and accessing support	Burroughs et al (2006) Chew-Graham et al (2002) Hinrichs et al (2012) Lester et al (2005) Prasad et al (1999) Railton et al (2000) Reid et al (2010) Roberts et al (2013)

Figure 1. Flow diagram for inclusion of papers in the meta-synthesis



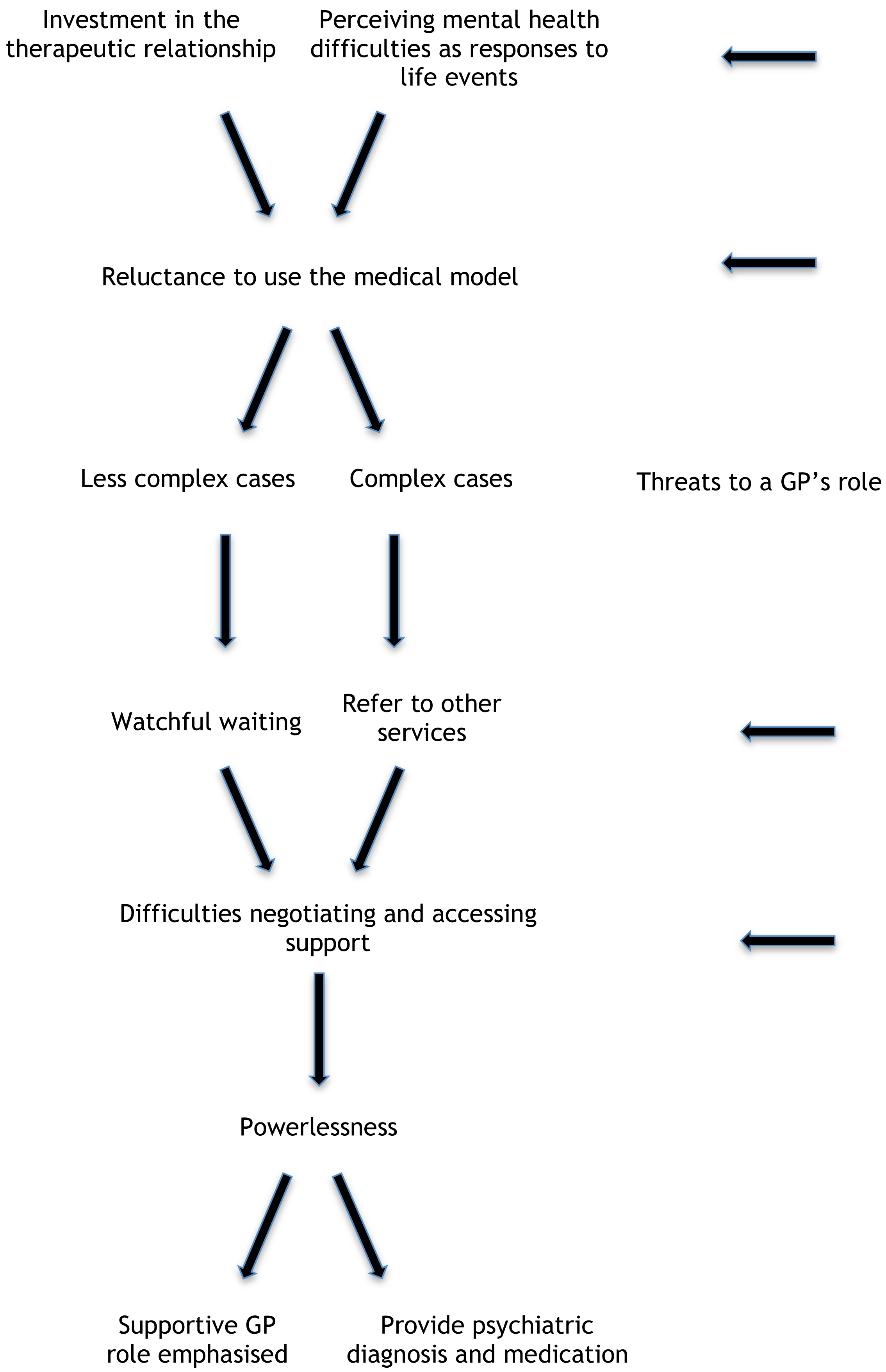


Figure 2. Thematic map of main processes and dilemmas GPs may experience during consultation

Appendix A

British Journal of Clinical Psychology Instructions for Authors

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:
- Papers reporting original empirical investigations
- Theoretical papers, provided that these are sufficiently related to the empirical data
- Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications
- Brief reports and comments

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The word limit for papers submitted for consideration to BJCP is 5000 words and any papers that are over this word limit will be returned to the authors. The word limit does not include the abstract, reference list, figures, or tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length. In such a case, the authors should contact the Editors before submission of the paper.

3. Submission and reviewing
All manuscripts must be submitted via http://www.editorialmanager.com/bjcp/. The Journal operates a policy of anonymous peer review. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.

4. Manuscript requirements
- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
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- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading

should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.

• All papers must include a structured abstract of up to 250 words under the headings: Objectives, Methods, Results, Conclusions. Articles which report original scientific research should also include a heading 'Design' before 'Methods'. The 'Methods' section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.

• All Articles must include Practitioner Points – these are 2–4 bullet points to detail the positive clinical implications of the work, with a further 2–4 bullet points outlining cautions or limitations of the study. They should be placed below the abstract, with the heading 'Practitioner Points'.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

5. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000 words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table or figure, which should only be included if it conveys information more efficiently than the text. Title, author name and address are not included in the word limit.

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Running Head: RECEIVING A DIAGNOSIS OF BIPOLAR DISORDER

Section Two: Research Paper

Receiving a diagnosis of bipolar disorder: Individual stories within the dominant medical narrative

Roisin Turner

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

All correspondence should be sent to:
Roisin Turner
Doctorate in Clinical Psychology
Lancaster University
Lancaster
LA1 4YG
Tel: 01254
Email: r.turner3@lancaster.ac.uk

Prepared for submission to Journal of Mental Health[1]

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[1] See Appendix A for author guidelines

Abstract

Background The medical model is a dominant narrative within mental health, and it has many implications for service users in terms of the language used, diagnosis and intervention options.

Aims The aim of this study was to explore service users' narratives regarding their journey to and following receiving a diagnosis of bipolar disorder, and explore the personal meaning of receiving a psychiatric diagnosis.

Method Narrative analysis was used to enable 12 participants to tell their story. The analysis took into account the wider social aspects, in particular the medical model narrative, and explored how these influenced the participants.

Results The meta-narrative was divided into phases of time to illustrate how the stories unfolded. These phases were: Life before diagnosis; The journey to diagnosis; Receiving a diagnosis; Since diagnosis; and The future.

Conclusions The findings highlighted that participants found receiving a diagnosis brought them relief due to an acknowledgement of their difficulties, however the diagnosis process and ensuing treatment options often created additional challenges for them.

Receiving a diagnosis of bipolar disorder: Individual stories within the dominant medical narrative

Bipolar disorder (BD), formally known as manic depression, is a psychiatric diagnosis given to people who describe experiencing alternating episodes of both extreme high and low moods (American Psychiatric Association, APA, 2013; World Health Organisation, 1992). These high moods, also known as mania, are described as racing thoughts, delusions of self-grandeur, partaking in risky behaviors and reduced need for sleep. During depressive periods, service users commonly report experiencing reduced mood, changes in appetite, and irritability (APA, 2013). There are a number of identified types of bipolar diagnoses, the main two being bipolar I and bipolar II (APA, 2013). According to the Diagnostic and Statistical Manual of mental disorders (DSM-5, APA, 2013), bipolar I is characterised by the experience of manic episodes and usually episodes of depression; the severity and duration of episodes are often severe. ‘Manic’ episodes may involve experiencing an intense sense of well-being and energy which may impact on decision-making and involvement in risk-taking behaviour. Bipolar II is characterised by the experience of hypomanic and depressive episodes; hypomanic episodes have a less severe impact on the person’s functioning than manic episodes. Those diagnosed with BD are associated with significant mortality risk; it is reported that those diagnosed with BD have a suicide rate approximately 20–30 times that of the general population (Pompili et al., 2012).

In terms of receiving a diagnosis, it is estimated that 1 to 1.5 per cent of the population are likely to receive a diagnosis of BD at some point in their life (Division of Clinical Psychology, DCP, 2010). An online survey of people who have been diagnosed with BD and their families (carried out by Bipolar UK, Bipolar Scotland and the Royal College of Psychiatrists, 2012) showed that many people were diagnosed more than 13 years after they had first started experiencing symptoms. Eighty-five percent of more than 700 people surveyed were initally diagnosed with a different diagnosis, most commonly depression, before they received a diagnosis of BD. Misdiagnosis is one of a growing number of criticisms of the medical model and psychiatric diagnosis (Pilgrim, 2007), and the DSM-5 has stimulated professional debate about its reliability and necessity (DCP, 2013).

One critique of psychiatric diagnosis is that it was not designed to and consequently does not inform us of the underlying cause of the difficulties (DCP, 2010; Mellsop & Howard-Clapham, 2012). It emphasises the biological aspects of mental health difficulties meaning an over-emphasis on interventions such as medication, and lessening the psychosocial factors of people’s distress (Boyle, 2013; Cromby & Harper, 2013; Moncrieff, 2008). It has been argued that it reduces psychological responses to experiences into a label which removes the individual’s personal meaning (Johnstone, 2006). Another major criticism is that psychiatric diagnosis is founded within the Westernised worldview, and therefore does not reflect other cultural views regarding behaviour (e.g. Busfield, 1996; Fernando, 2010; Shaw & Proctor, 2005). Psychiatric diagnoses tend to favour the individualisation of distress, putting it into reductionist categories, and then associating it with underlying biomedical pathologies (Bentall, 2004; Boyle, 2002). The categories are poor predictors of outcomes, interventions or even of people's 'symptoms' (Bentall, 2003; BPS, 2000). There is strong evidence that emotional distress and behavioural problems are understandable responses to or ways of actively trying to manage adverse circumstances and relationships (Albee, 1986; Johnstone, 2000; Smail, 2001; Stoppard, 1999; Wilkinson, 2005). The negative stigmatising effects of diagnostic labels are also a contest to their use, both in terms of public stigma (Corrigan, 2000; Penn & Martin, 1998) and self-stigma (Corrigan, Faber, Rashid, & Leary, 1999; Link, 1987; Link & Phelan, 2001).

The medical model could be described as a dominant narrative within the UK mental health system, for example, the way mental health is defined, discussed and approached. Although it is a common medical approach in clinical psychiatry, which focuses on diagnosis and medication, not all psychiatrists follow this approach (Pilgrim & Rogers 2009). Many are dedicated to alternative perspectives, such as social causationism and social constructivism (Pilgrim, Kinderman, & Tai, 2008). Service users' understanding of mental health is understandably often based on the dominant medical model narrative, but other understandings of mental health are acknowledged such as being a response to social and environmental factors (Beresford, Nettle, & Perring, 2010). Environmental factors such as poverty, unemployment, and social exclusion, and life events such as sexual, emotional, and physical abuse have strong associations with mental health difficulties (Marmot & Wilkinson, 2006).

As part of the above critiques there are strong movements from clinical psychology in the UK in particular for a move away from psychiatric diagnosis and to view mental health difficulties as multidimensional and on a continuum of human experience (DCP, 2013; Gill, Mullin & Simpson, 2013). Written material has been produced for service users and professionals as an aid to promote further understanding and encourage psychological considerations of those diagnosed with BD (DCP, 2010; Jones, Heywood, & Lam, 2005). The DCP (2010) visualises mental health as being on a continuum and implies that services should not insist that service users label their difficulties as an 'illness' and they should be offered information and choice regarding help and support they can access. Charity organisations, such as Mind and Rethink, have also become more vocal regarding the use of diagnoses and the potential impact upon individuals. The chief executive of mental health charity Mind, Paul Farmer, has stated that although a diagnosis can give people access to treatment, support and services, there are the negative aspects such as receiving the wrong diagnosis, stigma and having a label (Mind website, 13 May 2013).

Professional bodies have highlighted the importance of service user views with this debate, for example, the UK and International Critical Psychiatry Network, and the DCP. The DCP (2013) report that despite the criticisms, service users can find that diagnosis has some benefits, for example, offering assurance that they are not to blame for their difficulties (Bringewatt, 2013). Dinos et al (2004) found that service users who had received various psychiatric diagnosis across the sample, including BD, disclosed negative experiences such as stigma and discrimination. However some also expressed relief in receiving a diagnosis, and others thought that through acceptance of their diagnosis they as a consequence were better adjusted. Howe, Tickle and Brown (2014) identified in their qualititative study that people diagnosed with schizophrenia described how professionals often did not explain what the diagnosis meant which limited their acceptance of the diagnosis, and the focus on biological causes led them to liken it to physical illness thereby limiting hope for recovery. In contrast, Pitt, Kilbride, Welford, Nothard and Morrison (2009) found in their sample of service users who had been given a diagnosis of psychosis that diagnosis opened the door as a means of access to treatment and helped by 'naming the problem', however for some it also caused disempowerment, social exclusion and hindered by 'labelling the person'. Avoidance or withdrawal can be used as a coping strategy for stigma, which then in turn leads to social isolation and social exclusion (Knight, Wykes & Hayward, 2003).

Inder et al (2010) conducted a qualititative study in New Zealand asking participants about their experience and how they made sense of their BD diagnosis. The participants shared their frustrations about the lack of explanation regarding their diagnosis and experiences and being diagnosed on multiple occasions with numerous different psychiatric diagnoses. Others stated that a BD diagnosis did help to make sense of previous difficulties they had experienced, and it assisted to validate their experiences. The authors concluded that receiving a diagnosis was an active process which involved seeking validation and ongoing questionning of the accuracy of the diagnosis. It is argued that the experience of stable periods can increase the doubt and ambivalence of a diagnosis (Goodwin & Jamison, 2007). Until recently the diagnosis of BD has been relatively neglected within research, when compared to other mental health problems with comparable prevalance rates and impact, such as schizophrenia (Jones & Bentall, 2006).

The aims of this research are to explore peoples' narratives regarding their journey to and following receiving a diagnosis of BD, and explore the personal meaning of receiving a psychiatric diagnosis. This will enable professionals to gain a greater insight into the range of impacts that receiving a psychiatric diagnosis can have for service users, and add service users voices to the debate of the current system of diagnosis. Using a narrative perspective acknowledges the personal meaning of an individual's story and recognises that this view of their world is expressed within a wider social context which may limit the selection of culturally acceptable plots (Riessman, 1993). Through exploring and comparing personal narratives the study aims to provide a deeper understanding of how people with a diagnosis of BD create sense of their experiences, how they navigate challenges and therefore how this sculpts their personal identity.

Method

Design

In this study a qualitative design was employed in order to explore the stories of adults who have received a diagnosis of BD and to allow them to share full accounts of this experience. Narrative analysis as a qualitative approach was chosen because it allows the listener to hear how the participants made sense through sharing the stories of their experiences and the impact this has had on them. Using narrative analysis enabled the researcher to look at the participants as whole people and to explore the details of their experiences (Riessman, 2011). It ensures that the individual's voice is not lost through analysis by the production of individual narrative accounts (see Appendix C). The participant directs the interview and thus the content and process by which they decide to share their story can be attended to; often what a participant decides not to share may be as important as the information they do communicate. The researcher read the transcripts as if they were the personal accounts of the individual's life, keeping in mind that narrators interpret the past rather than replicate it as it was (Riessman, 2005).

The focus was to represent the participant's life story narrative as a journey into an identity of a person who has been given a diagnosis of BD. Personal narratives not only emerge within a certain social context but also in relation to cultural norms and what is the ideal of a 'good life' (Freeman & Brockmeier, 2001). Narrative analysis not only allows the participants to tell their story (Riessman, 2009) but can also take into account the wider social and cultural aspects and how these influence the individual (McCormack, 2004). Narrative analysis enabled the researcher to attend to both the content of the stories and how the stories were told by participants; therefore providing a rich understanding of their experiences. A brief interview schedule was developed which consisted of open-ended questions used to initiate the storytelling process. This allowed participants to have control over the direction of their interview whereby they could recount the key events in their lives and created possibilities for extended narration (Riessman, 2009, McAdams 1993).

Sampling and Participants

Participants were recruited from a mental health research centre located in a University in the UK, and from a UK national charitable organisation (Bipolar UK) that supports people who have received a diagnosis of bipolar disorder. The study included males and females aged over 18 years who had received a psychiatric diagnosis of bipolar disorder and lived in the north-west of England. A total of 189 people were sent information about the study and 21 potential participants contacted the researcher and expressed an interest in taking part. Of these four lived outside the North West and it was not feasible to visit them within the constraints of the study resources, three did not get in contact again after their initial interest and two decided not to participate due to personal reasons which were not related to the research. The remaining 12 completed the demographic information form and agreed to meet for an interview (see Figure 1 for a diagrammatic representation of the recruitment process). The final sample (See Table 1) consisted of eight females and four males, all white British and aged between 33 and 70 years (average 50 years).

<Insert Table 1 here>

Ethics

The research study was discussed with a service user Advisory Panel at the research centre who helped plan the recruitment strategy, the interview schedule and how to manage potential ethical issues. Ethical approval was gained in September 2014 from the Faculty of Health and Medicine Research Ethics Committee and the University Research Ethics Committee at Lancaster University.

Prior to interview each of the 12 participants were emailed an information sheet about the study and were asked to complete a demographic form which included providing contact details for their General Practitioner (GP) or Care Co-ordinator. This allowed the researcher to check if there were any risk issues prior to interview, and also provided a contact if a participant shared information during or immediately after the interview that indicated any potential risk to themselves or others. The participants were also emailed the consent form (see ethics section no 4, p. 22-23), and this was completed with the researcher before the interview commenced. The researcher provided opportunity for questions to be raised and asked them to supply a pseudonym to ensure confidentiality of their identity. Following each interview the participant was given a debriefing sheet (see ethics section no 4, pp. 26-27), which provided a reminder of information relating to the study and emergency contact numbers.

Data Collection

Interviews took place at the participants home (n = 5) or the University (n = 7) depending on participant preference. The researcher commenced each interview with the broad open question, “Tell me about your experience of being diagnosed with bipolar disorder”. Additional prompt questions (see ethics section no 4, p. 27) were asked to encourage elaboration and these linked to aspects such as life chapters, key events, significant people and future script (Crossley, 2000). Each interview was audio-recorded and the interviews lasted between 50 and 93 minutes.

Analysis

Narrative analysis aims to study the language, stories and narratives that people share (Crossley, 2000). Narrative analysis prompts the researcher to look beyond the surface of a story and consider the how and why a story is relayed in a particular way and what impact this may have on the listener (Riessman, 2009). It is a diverse methodology and a number of different analytic approaches can be taken (Polkinghorne, 1995; Smith & Sparkes, 2006) depending on the aims of the research. As an aim of this study was to establish a joint narrative across the transcripts, guidance was followed from Crossley (2000) to achieve this. The transcripts (see Appendix B for example excerpt) were read and re-read to develop familiarity with the structure and content, and individual summary stories were then constructed (see Appendix C). The summary stories were placed in chronological order in terms of before diagnosis, at the time of diagnosis and reflections since diagnosis. They focused on key experiences and the narrative processes and factors, which included language, imagery, identity, and emotion (Crossley, 2000; Weatherhead, 2011).

Each story was returned to the participants to check for accuracy and feedback was invited to explore the impact of this process. All feedback was positive and no amendments were requested. Comments included: “It's a very compassionate and understanding précis of our interview, thank you” (Ben); “It reads really well, I'm glad I said all those things you recorded and I still agree with it all and feel that way about a diagnosis of bipolar. Good stuff” (Tom); “It was very strange reading me from an objective perspective before. Very odd. Thank you for all the work that went into it” (Joy); and “I have read the summary numerous times and am happy with it, well not happy, it was quite upsetting. It is a true reflection of your interview though" (Mary). The summary stories were then compared, facilitating the emergence of a shared narrative based around five phases.

Reflexivity

Qualitative analysis involves an increased level of subjectivity as it is shaped by the authors' own interpretations of the interview data. Transparency is therefore central to allow for reliable research to be undertaken, and a reflexive approach has been adopted within this research to enable this. The principal researcher takes a social constructivist approach which views that there is no emerging 'truth' within the findings (Riessman, 1993) and the narratives are contextualised in relation to a person's environment, culture and the dominant narratives of that society.

The principal researcher is a trainee clinical psychologist currently in her final year of training. She has had some clinical experience working with service users who been given a BD diagnosis. Clinical training and personal values may have influenced how she read the data and decided the interview data to include. Although these biases are inevitable and can be useful in directing analsysis and research (Bannister, Burman, Parker, Taylor, & Tindall, 1994), it is vital that the individual narratives are not misinterpreted. To minimise this a reflective diary was kept to reflect on interactions between researcher and the research throughout the study. An academic supervisor independently read through sections of the interview transcripts to ensure validity. Finally the narrative summaries were shared with the participants to check for accuracy to ensure that integrity have been kept.

The first supervisor is a health psychologist and academic with a particular interest in chronic illness and mental health. The second supervisor is a clinical psychologist and academic with expertise in the development and evaluation of psychosocial interventions for people with mental health problems and their families.

Findings

A narrative analysis of the 12 interview transcripts is presented in the form of a shared story or meta-narrative. Excerpts from the interviews are used to highlight similarities and differences and to draw attention to significant features. Throughout this section, (..) denotes a long pause and [...] denotes omitted material. Although participants did not share their stories in chronological order, commonalities in the narratives were used to develop a meta-narrative structure. The meta-narrative has been divided into phases of time to illustrate how the stories unfolded. These phases are: Life before diagnosis; The journey to diagnosis; Receiving a diagnosis; Since diagnosis; and The future.

“Not being understood and disregarded”: **Life before diagnosis**

This phase of the participants’ narratives highlighted their lives prior to receiving a diagnosis. The majority of the participants shared personal aspects of their childhood, which included either difficult or traumatic relationships with a caregiver or with peers. There were themes of loss (Adele, Ben, Claire, Tina, Tom), sexual abuse (Joy, Martin) feeling criticised (Kim, Poppy), feeling they had not met the high expectations set from parents (Mary, Poppy), and as an adult, changes in the family such as children leaving home which impacted on their sense of identity and role within the family (Alice). The majority of participants stated that they "knew something was wrong" with them, for example, Joy stated: "Feeling that I was just bad and naughty and irresponsible, er feeling that something was terrible terribly wrong with me and I mustn't tell anybody about it, not even you know to acknowledge it". There was a sense of feeling hopelessness: "I'm so fed up after 31 years of not being understood and disregarded" (Kim), and feeling alone was common, for example: "When I went home, I'd lie down on my face on the bedroom floor and I'd cry my heart out" (Martin); "My parents didn't know half of what went on in my head because I didn't divulge most of what went on inside my head" (Poppy); and "I lived a solitary life for five years when I was at that school […] I was nothing to nobody" (Tom). One participant, Sammy, did not share anything of his life prior to the experiences at the time of diagnosis, and Alice described her teenage years as "quite dark" and did not expand on this. Metaphors and descriptions for these years included: "the wilderness years" (Sammy), "the hell bit" (Adele), "it's the road into the abyss and you don't want to go there" (Martin), and "black black, dark dark" (Joy).

Most of the participants only shared earlier life experiences when specifically asked to towards the end of the interview when asked about the chapters of their lives. It is interesting how some of the most significant and revealing parts of their life would have been missed or unsaid without prompting. Perhaps they do not think it to be significant in terms of their diagnosis, for example Joy described an aggressive takeover of the company she worked for that "caused me to flip, erm it wasn't the result of suicide attempts or anything like that, it was plain normal life that I couldn't handle", and, "It came out of the blue". However her employment situation only appeared to be the trigger for her mental health difficulties; she described traumatic and difficult events earlier in her childhood which may have been significant. Joy stated "I actually had a relatively nice childhood", and then later disclosed: "I suppose I was molested um as a child by a neighbour", and "I've always known I was gay but in a white (name of country) hyper Calvinistic conservative society that was a no no". She described herself as "fractured inside, I always knew that, I was always not like other people […] once the crack was cracked I could never get it back […] I always had that vulnerability, that fragility in me." It appears that, as with Joy, most of the other participants also did not consider the potential significance of early childhood experiences on their mental health.

***"If you don't have a diagnosis you're left in limbo"*: The journey to diagnosis**

The journey to diagnosis for the majority was not chosen and was ensued after a time of crisis or hospitalisation. Ben, Mary and Martin however sought diagnosis after periods of experiencing high and low periods in their lives and wanting support and help with their difficulties. For all though it appeared that diagnosis for them represented gaining acknowledgement for the difficulties they had faced. Ben in particular pushed for his diagnosis because, "If you don't have a diagnosis at all you're left in limbo, nothing, access to nothing, erm but if you have a diagnosis there's the potential for further care". Ben's perceived his answer to his difficulties to be medication rather than a diagnosis, but he was caught in a "Catch-22" situation in which he was unable to access the medication unless he had a diagnosis. His GP told him that, "'I could see that possibly lithium could be useful to you, erm but I can't prescribe it unless I've got permission from a psychiatrist to do that, and the psychiatrist can't do that unless you've got a diagnosis'".

Kim's journey differed to the other participants. She did not ask to see a psychiatrist; she had years of input from a clinical psychologist and had built a support network based on the Soteria Network principles. The Soteria Network is an international movement of service users, carers and professionals who promote the development of drug-free and minimal medication therapeutic environments for people who experience hearing voices. However when Kim moved she went to her new GP to ask to see a clinical psychologist to continue her support, but she instead sent Kim to a psychiatrist. It appears that Kim's wishes and needs were not heard by her GP, and instead she was pushed onto a different path. She described the psychiatrist as being "extremely perplexed" because she had not been admitted to hospital at any point and was not taking medication. Kim at this point said she felt annoyed because she felt that she was not being heard or being taken seriously: "If I'm in crisis I automatically go into Soteria gear […] that was the way I was helped in the beginning and that's how I've continued, so the mental health services haven't really got involved and they don't seem to take me seriously or they just assume I'm doing a lot more well than I actually am". She said that "because I just hadn't got a diagnosis I was fed up of saying, 'Well I think there's something wrong', and then them just saying, Oh no, you're fine'". For Kim having the diagnosis signified that she was being taking seriously and for this it was a relief for her, particularly as a child she felt she did not have a voice either. Kim went on to say that, “Quite a few people that have been through the system they’re just used to that one route […] if I’d been somewhere else they might have said, ‘Right we’ll put you on a ward and drug you up’”.

For those who were in hospital and were not actively pushing for a psychiatric diagnosis, it raisies the issues of consent particularly as it often occurs when someone is in crisis which limits potential collaboration: “You’re not in a good place anyway you know, to receive things so I think the way I was things sort of went over my head really” (Alice). It appears that the participants are steered onto one path from which there are no alternatives offered, or if they have journeyed down a different path at some stage this is met with confusion and dismissal, for example, with the Soteria Network: “It sounds too good to be true um and it lots of ways it was too good to be true but I don’t think people really believe it, and especially psychiatrists, you know, I think he was really pleased to give me this medication because he felt that was his role” (Kim).

“It doesn’t give you any solace”: Receiving a diagnosis

The third phase relates to receiving the diagnosis of BD, the messages that the participants received at that time and their feelings regarding this. For all the participants there was emphasis on a medicalised message, for example, possessing a ‘chemical imbalance’, which was a ‘life-long illness’ or ‘chronic condition’: “Chemical imbalances were mentioned, that’s why I’m given chemicals in a way to rebalance myself and that’s why it’s a sort of balancing game, you know, one goes down and the other has to be brought down to level it” (Adele). It was often likened to having a physical health condition: “The comparison is always made with diabetes and people taking insulin” (Claire), and Alice stated that: I suppose it’s like.. well I don’t know, say some other disease that’s not going to be fatal but it’s going to be life-long and need life-long treatment, I suppose say like epilepsy”. The dominance of the medical model narrative ran throughout all the participant narratives, even when not specifically talking about it, for example, feeling “fractured” or “broken”.

Adele, Alice and Poppy disclosed that their diagnosis was not verbally shared with them, rather it was read in a file and they approached this with a staff member: “It’d be a form with my name on and everything and at the top I read bipolar disorder and I said, I must have thought, ‘Well if it’s a disorder is that what’s wrong with me?’ and she sort of, ‘Oh did you not know?’” (Adele). For those who sought a diagnosis there appeared to be an assumption from the psychiatrist that they had information about it: “She was quite nice but functional and didn’t sort of tell me an awful lot because I’d gone to her with it so she knew you know I’d sort of […] the assumption there was that I knew anyway because I’d gone to them with it” (Mary). Alice talked about her “conscientious psychiatrist” who “didn’t want to saddle me with the wrong diagnosis” and shared his opinion with her; however Alice’s opinion was not asked for or provided when a decision regarding diagnosis was being made.

The way the message was given to the participants appeared significant to their feeling towards the diagnosis at the time. Those participants who were given the diagnosis whilst in hospital generally found it to be a negative experience: “I was so unwell that I wouldn’t have been able to take on board any of that kind of side of it" (Claire). The demeanor of the psychiatrists was also mentioned, for example, "She was very detached, there was no emotion in her" (Martin). Kim stated that she would have liked her psychiatrist to have explained why he thought she had BD: "Cos when you think about it he'd only met me what five, ten minutes, so it's not because he's known me […] he could have explained far more […] with psychiatrists I just don't feel you can have a dialogue at all". The words used within the message appeared to have stayed with the participants: "It was weird, the psychiatrist said I was actually by the book" (Joy), and "She was like, 'Well you've got these but you haven't got these', and it's like wow, okay, wow, this is how we're doing this" (Ben). Joy said that the psychiatrist who diagnosed BD "asked the right questions", and:

> She knew exactly what she was doing, she explained it to me really well […] she said, 'Take your pills, stop drinking and you'll be fine', […] that it wasn't a terribly bad thing um, she told me that her sister was a QC and so I had her kind of positive spin. (Joy)

The participants shared their initial emotional responses to their diagnosis, and for the majority there was relief: "It made absolute sense […] so it was a relief for me" (Mary); "I think I found it a relief um, to have the label because although you might say it means you have a mental illness, to me I knew I had something that was causing a lot of distress so to have a name for it felt helpful" (Poppy); and, "It was a sense of relief because it confirmed that there's been something wrong with me […] we now know what's wrong, and you're not a bad person" (Martin). Claire expressed resentment however, and summed up the feeling that the other participants felt in terms of a lack of hope given at the time of diagnosis: “People should have more hope than what they’re being given’”. Tom likened it to “chucking a live grenade in a room and then bombing it, you know, more needs to be done to say this is manageable, we can cope with this, you can cope with this”. The ‘disease’ or ‘illness’ explanation appeared to give some participants hope initially: “People can manage diseases” (Joy); “I thought, ‘Well that was then this is now, onwards and upwards sort of thing’ (Mary); “I had this feeling that, ‘Well then they can fix it so now we know’” (Poppy). However this was soon quashed: “That was quite quickly replaced by feeling very very sad and miserable about it, erm, because I thought it just sort of defines my whole personality really, erm, so yea, initially I was pleased and then that was soon replaced by sadness” (Mary), “‘Some of that positivity of having a diagnosis disappeared when I realised even now you know what it is, you don’t know how it’s caused or how it works in the body yet […] disheartened really since the diagnosis” (Poppy), and “It doesn’t give you any solace, you still go, ‘What’s wrong with me?’” (Ben).

***“It’s insurmountable, unfixable”*: Since diagnosis**

The common aspects of participant’s reflections included the positives and negatives of having a diagnosis, how diagnosis can influence self-perceptions and responses to others, and their ability to question aspects of their care.

All the participants shared how having a diagnosis has enabled their lives, for example, having access to services, medication and interventions. Ben summed up the main positives and negatives of having a diagnosis, and described it as both as “shackle” in terms of being limiting for example with employment and travel, but also a “passport” in that it opened access to medication, psychological input and support. He described it as a card: “Sometimes that card can be accepted or be declined”, depending on where you want to use the card. For most participants there were variations in their narratives in which they initially shared the more positive aspects of diagnosis but then went onto say how it limited their life:

> “If I didn’t have a diagnosis I wouldn’t be able to get a care co-ordinator, I wouldn’t fall into the NICE guidelines, I wouldn’t be able to have, to be in the secondary mental health services […] I wouldn’t recommend people not to get a diagnosis, I think it would help if they didn’t have a diagnosis but the, the social society’s not set up to help people without a diagnosis in this country”.

The language of diagnosis was conveyed within a number of narratives, and what this label meant to them and how it influenced their interactions with others. Tina stated that she would prefer to use a more ‘common’ and ‘understandable’ term such as stress particularly when explaining it to other other: “So I’ll use that as a label rather than labelling myself so that it doesn’t have the same hints of disability um, because it is still quite hard as I say I still see it as almost a stigma really”. Claire stated that:

> I don’t think I am a dysfunctional person […] a diagnosis does seem dysfunctional and disordered […] it’s always about the negatives a lot of the time […] I don’t know whether it would just be helpful just to have it termed like the fact that you were distressed […] actually acknowledging the things that were around that made you distressed.

Ben shared that he felt it was easier to tell others that he was gay: "People understand it unlike mental health", and Joy stated that "I'd rather tell somebody that I'd had a drinking problem rather than them know I've got bipolar, isn't that interesting [...] I feel more ashamed about having that than being an alcoholic, how awful is that".

Joy stated that she uses her diagnosis as a way of taking responsibility: "I don't use it as an excuse um, I use it as a responsibility that I need to take it in order to make my life better", and Tina acknowledged "It's very easy with bipolar and certainly I found it easy recently to just say, 'I'm just feeling depressed' [...] I think it's unhelpful in that way in that you can sometimes not take responsibility". A number of participants said however that since having the diagnosis they have become kinder and more accepting of themselves: "It helps you to be more gentle with yourself because you realise that you have got a very serious condition (Kim); "I can be more accepting for being me now, whereas I've had to hide things in the past, or you know, say if I was okay if I wasn't" (Mary); and "When you've got a diagnosis you can say, 'Well it isn't me, it's my bipolar, so I'm okay', so it protects the individual from self-doubt, from self-recrimination, from guilt, from shame" (Tom). Poppy stated however that if her difficulties were seen as individual aspects or personal characteristics then she may find these easier to manage and accept rather than "see it as this huge bipolar thing which I see as probably insurmountable, deep down I probably feel that it's insurmountable, unfixable".

Some of the participants shared that they have on occasions questioned their medication, or since reflected upon decisions they made.

Some of this links to the authority that professionals have, and how this is unlikely to be challenged: “I followed his instructions and um he’s right […] that’s unhelpful thinking that I know better than the medical man, woman I should say” (Martin), and Ben reflected on “how much kind of precedence and primacy I place in the judgment of medical professionals”. Tom also shared: “I think my upbringing and the fact that I’ve been part of a family who’ve always you know felt the professionals have the answers and you know you listen to professionals”. Ben also alluded to the fact that the language of diagnosis can also impact on how much control a person may feel they have over their lives: “By telling someone, ‘I have bipolar disorder’ you are presenting with a range of possibilities that may occur […] you’re almost presenting the bipolar disorder as having agency over you, erm through the use of language” (Ben).

***“It just seems really bleak”*: The future**

The participants were asked what future chapters they foresee for their own personal lives, and for many this appeared to be a difficult question. There was a lack of hope for many: “I haven’t got any inspiration really for the next ones (..) so I don’t know really about the future” (Alice), and, “I’ve got to be really honest and say it just seems really bleak” (Kim). Mary stated that she takes each day as it comes, and her focus is to be a really good mother for her son: “On paper it’s not looking brilliant for him is it really, erm, so it’s up to me to make sure you know, cos I’ve read about parents er children of parents with bipolar disorder and you know all the categories that he fits into, seriously the future doesn’t you know, on paper it doesn’t look rosy for him”. Tina spoke about medication and how, "Ideally I wanted to be back you know where I don't need any medication and I'm back to where I used to be but that's not going to happen, um, you know there's this kind of running away from it all and hoping that you wake up and it will have been a big dream". Poppy also stated, "I've not met a single person who says they're bipolar and thinks they have been fixed [...] I would probably say my medication is working pretty well right now, but fixed where I think I won't have a problem in a year or two years or four years, no".

Some of the participants shared how they would like to see changes to services for the future based on their experiences and knowledge. Ben stated that there should be pre- and post-counselling available for those who have received a diagnosis, and likened this to HIV counselling after a diagnosis: "I think we're talking about things that can have such life changing, the diagnosis itself is a paper based and labeling exercise, it can be so disabling beyond the condition itself" (Ben). Claire considered the messages at the time of diagnosis and stated that "just acknowledging that you were distressed and those were the things that led to that distress at that time, and maybe they don't hold forever". Poppy also stated that diagnosis can be used as a shorthand which can be useful when explaining their difficulties, but "it means you're not looking at the whole picture [...] there's so many other factors but no doctor has the time to listen to every single factor and look at you as a whole person". Other potential changes were also hampered by the pessimism of how the current system could be transformed: "If I had the opportunity to go to therapy more than once a week for a period of time [...] if I had that opportunity I'm sure I would do it but I don’t so I had to take the opportunity which is cheapest for the NHS” (Ben). Kim also alluded to this saying that she would prefer to have group therapy with a clinical psychologist rather than a diagnosis, “cos it would give me that um balance and um and I’m sure that’s probably why I didn’t end up in hospital […] the irony of it is the help I got before the diagnosis was better than I had after the diagnosis” (Kim).

For all the participants accessing support in their community and self-help groups played a vital role in their recovery. There was a sense of “camaraderie and being in it with somebody else makes it more bearable” (Tina), “You realise I’m not the only one” (Tom), “Hearing other people’s stories” (Claire), and Poppy talked about the classes she was able to access in the community: “I think everyone should be entitled to those things for free […] then maybe so many of us won’t become unwell in the first place”. She was heartbroken when the woodwork classes she attended were cut which illustrates the significance to her: “Which was heartbreaking to me and I campaigned and protested cos I thought it saved my life at the time”.

Discussion

The aim of this study was to hear the narratives of those who have been given a diagnosis of BD and the personal meaning of receiving a diagnosis, and to consider this within the dominant narrative of the medical model. The participants’ journey consisted of five phases which incorporated their perspectives and emotional responses to their diagnosis. The research found that psychiatric diagnosis has both a positive and negative impact on an individual. Diagnosis is powerful in that it validates some personal characteristics but can invalidate the self (Hayne, 2003). For participants it gave them a sense of relief in that their difficulties were being acknowledged, however the diagnosis process and ensuing treatment options often created additional challenges.

As part of the narrative process I also wanted to share the messages that service users spoke of during their narratives. I created three narrative poems that used the reported direct speech and direct thoughts the participants shared within their narratives (see Appendix D). These incorporated the messages they had heard from others, both professionals and family and friends, for example “she said”, and their own internal dialogue, for example, “I thought”. My basic assumption is that although these messages are based on real interactions they are represented by the participants in a reduced form. They highlight the prominent messages the participants took from their interactions with others and the type of language they use towards themselves. These forms of direct speech and thought used in the telling of narratives provide more vivid and engaging story telling (Clark & Gerrig, 1990; Yao, Belip, & Scheepers, 2012). The narrative poems show the type of language used by others and towards themselves as overwhelmingly negative. It illustrates the mixed messages they receive, and portrays their experiences as confusing and chaotic from the language they use. The language of disorder can negatively sculpt a person’s perspective on life, their identity and self-esteem (Barham & Hayward, 1995; Honos-Webb & Leitner, 2001).

Participants prior to their diagnosis shared their difficult experiences within their narratives and it appeared that they often did not have their needs met. These needs included feeling understood, acceptance, being listened to and seeking hope. Most of the participants' personal stories before diagnosis were not disclosed until much later in the interviews, and perhaps this signifies that these narratives are rarely asked or spoken about, and perhaps they are not viewed as 'good enough' explanations for their difficulties. The current classification system of diagnosis often means that service users will emphasise aspects of their experiences which are 'triggering' factors, rather than central factors (Beresford, 2013), as Joy did within her explanation of her work situation as a trigger to her mental health difficulties. This means that the significant life stressors and an individuals' personal history may not be addressed and become lost. It may however be unrealistic to expect service users to share these private and often difficult experiences in a short consultation with their GP or psychiatrist, and the focus on the medical model may not actively seek these narratives. Nevertheless hearing messages that their difficulties are an 'incurable disease' and their future life will mean possibly life-long dependency on psychiatric medication takes away any remaining hope.

Mishler (1986) states that "telling stories is one of the most significant ways individuals construct and express meaning" (p. 67). The journey for personal meaning is inevitably influenced by cultural and political influences (Saris, 1995). In current western culture the medical model is a powerful narrative that shapes how we view mental health, the language we use to describe it and how we help those with difficulties. Even those who take a different path, for example Kim, are escorted back: "Master narratives thus function as cultural standards against which community members feel compelled to position their personal experience"

(Thorne & McLean, 2003, p. 171). The medical model uses a reductionist discourse and expresses distress and trauma in terms of illness, disease, chemical imbalances and needing to be 'fixed'. However it does not account for individual experience and "explaining human unhappiness in medical terms is still nothing but a hypothesis, one which minimizes the possibility that people can change, grow, and develop" (Chamberlin, 1978, p. 110). Within the medical model experiences such as hearing voices are seen as 'abnormal' or 'dangerous', and therefore those who experience these are often silenced from fear of threat, stigma and isolation. How does one recover their voice and sense of self-worth following this? Raingruber (2002) conveys that seeking care and support can often be deterred as a result of stigma, and this therefore may increase an individual's feelings of powerlessness, isolation and hopelessness. Herman (1992) articulates that "helplessness and isolation are the core experiences of psychological trauma. Empowerment and reconnection are the core experiences of recovery" (p. 197). This might hold true for the use of medical model for some service users in that silencing their voice may be re-enacting any traumatic experiences that have encountered in the past. The Critical Psychiatry Network has voiced that modern-day psychiatry relies too much on the 'medical model' and they encourage psychiatrists to adopt a more social or therapeutic community approach (Double, 2000). Participants within this study mainly alluded to the dominant medical model, but they also made reference to other narratives such as trauma and loss, attachment theory and personality theories. Jacobson (2001) also found that participants in her study, which explored mental health recovery narratives, gave a range of explanations for their difficulties such as biological, abuse or trauma, and spiritual.

All the participants shared their involvement in self-help groups and how they value this support. Identity with groups gives us a sense of belonging, which arises from sharing personal narratives. The participants disclosed how the support groups allowed them to share and listen to each other's stories and provide a sense of camaraderie. Claire noted in her narrative that being on a long stay wards as an inpatient provided a degree of support with people who had similar difficulties. Community support now enables service users to discuss alternative ways of perceiving their mental health difficulties, for example, the Hearing Voices Network. Dillon and Homstein (2013) highlighted the positive aspects of peer support groups, such as providing empathy and identifying the strengths and talents of individuals that may not be noted in situations such as during an appointment with a professional. It helps group members feel validated and builds capacity for an individual to reflect and perhaps question the dominant narrative and treatment that they are offered.

Narrative analysis has and can affect social and political change. Plummer (1995) stated that “stories gather people around them” (p. 174) and can catalyse political actions, for example, moving HIV into the public eye. Currently service user networks in the UK in particular are becoming a more powerful voice within mental health, for example, the National Survivor User Network (NSUN) and the Hearing Voices Network. These survivor networks are helping to shift the medical profession to one where service users are starting to inform clinical practice and research. By reducing the dominance of the medical model language, service users are free to shape dialogue in their own language, and define their own version of their life narrative. In essence, they can form alternative narratives of mental distress and recovery and together with a network of voices can influence current shifts even further. It has been established that many recovery narratives include a rejection of diagnoses (May, 2000; Bassman, 2007; Longden, 2010). The clinical language that the medical model uses within mental health often determines how an experience is expressed, for example, a chemical imbalance in the brain rather than sadness, grief or distress. It does not allow an individual to choose their own language and pathologises experiences, seeing them as ‘problems’. Rather we need to give a voice to individual service users and help them construct more positive, empowering narratives.

Clinical implications

The present research emphasises the importance of enabling service users to have a voice rather than allowing the medical model to dominant their narrative. Using narrative approaches within research and psychological formulation within clinical practice will help enable service users to find their voice. Crossley (2000) states that through telling stories about their traumatic experiences, people can attempt to create a sense of order, meaningfulness and coherent identity. Clinicians must however be aware that some service users may feel anxious and cautious in contemplating an alternative to the more familiar medical model. The charity Mind (2014) has produced information for service users and those close to them which explains that there are alternative ways of thinking about their difficulties: “A lot of people, including some doctors, feel this medical model of diagnosis and treatment is not enough. Psychological and social factors – your background, lifestyle and other personal circumstances – may be just as important in diagnosing and treating you” (p. 10). Those aspects however of the medical model that have benefited service users, for example, providing camaraderie and support in a ward environment, need to be replicated in alternative ways, for example, through community support groups.

Limitations and recommendations for future research

The sample consisted of 12 participants, which provided rich interview data, however using a smaller sample would have allowed more detailed analysis. The sample also consisted of service users who were intelligent and driven individuals, and the majority were involved either in a university research group or service user support group. This may not be a representative sample of people who have received a diagnosis of BD. Future research could compare the specific impact of diagnosis by recruiting a group of service users who have not received a psychiatric diagnosis and those who have not. This could help explore the influence of the medical model regarding the language people use to share their experiences and how they perceive themselves.

Conclusion

This study provides a greater understanding of service users perceptions of psychiatric diagnosis and the messages they received at the time of diagnosis. Participant narratives highlight the positive and negative aspects of diagnosis, and how their journey to and following diagnosis has been influenced by the dominant medical model. These accounts provide an extraordinarily rich source of data, offering insights into the participants' lives. The findings suggest that enabling individual and personal narratives of service users experiences are important for recovery and providing people with empowerment and hope for the future.

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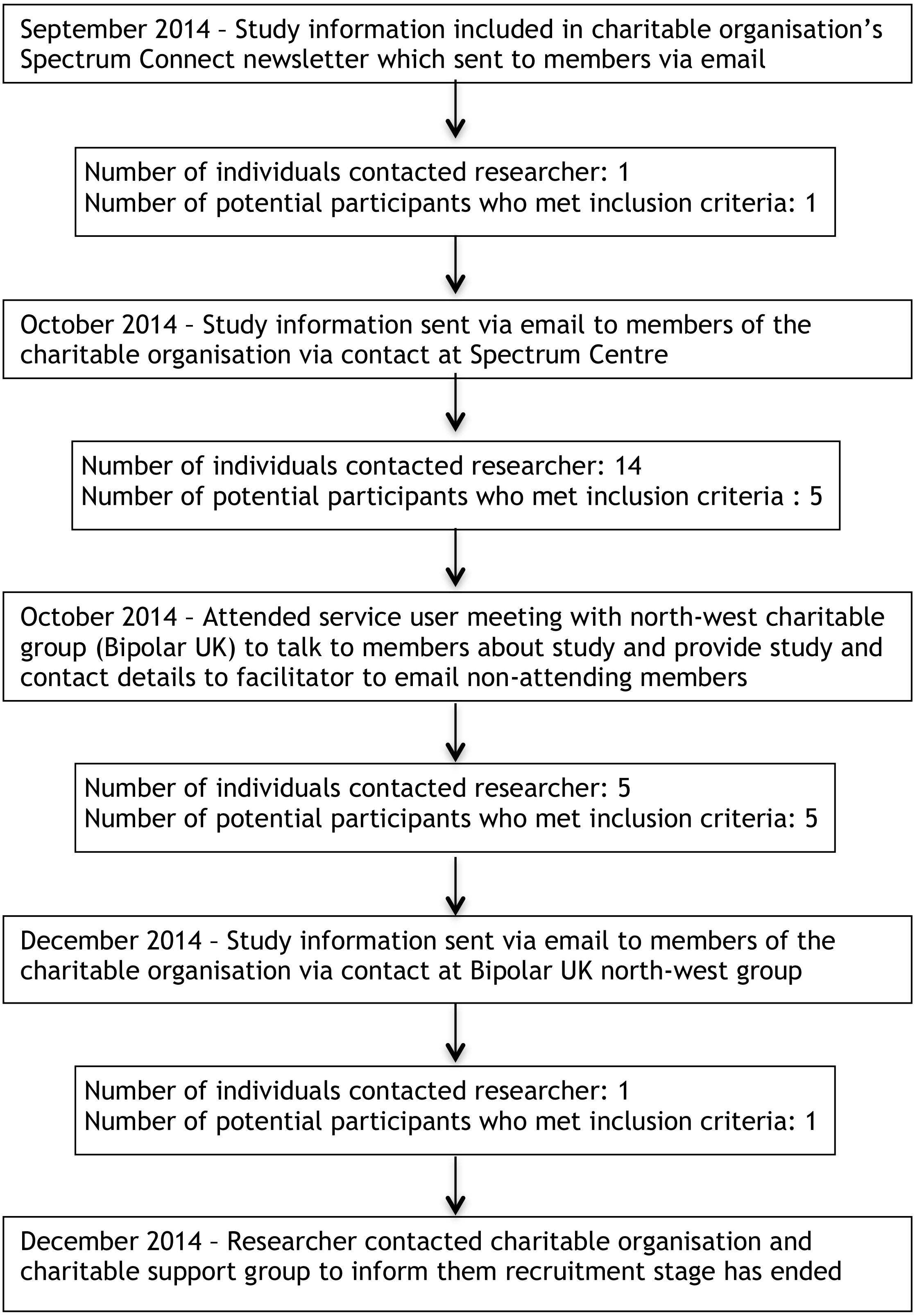
Table 1. Participant profiles

Participant	Gender	Age (years)	Ethnicity	Other diagnoses received	Number of years since received bipolar diagnosis	Marital Status	Work status
Adele	F	61	White British	No	13	Married	Retired due to redundancy
Alice	F	58	White British	Anorexia	10	Married	Sick leave from work
Ben	M	33	White British	Bulimia / Anorexia	10	Living with partner	Sick leave from work
Claire	F	35	White British	No	15	Single	Employed part-time
Joy	F	47	White British	No	9	Single	Full-time student
Kim	F	55	White British	Autism Spectrum Disorder	31	Single	Unemployed due to ill-health
Martin	M	70	White British	No	7	Married	Retired
Mary	F	51	White British	No	1	Single	Unemployed due to ill-health
Poppy	F	37	White British	Social Anxiety	37	Married	Retired due to ill-health
Sammy	M	60	White British	Narcolepsy	11	Married	Retired due to ill-health
Tina	F	49	White British	No	1.5	Married	Self-employed
Tom	M	39	White British	No	21	Single	Unemployed due to ill-health

Figure 1. Flow of recruitment process



September 2014 – Study information included in charitable organisation's Spectrum Connect newsletter which sent to members via email

Number of individuals contacted researcher: 1
Number of potential participants who met inclusion criteria: 1

October 2014 – Study information sent via email to members of the charitable organisation via contact at Spectrum Centre

Number of individuals contacted researcher: 14
Number of potential participants who met inclusion criteria : 5

October 2014 – Attended service user meeting with north-west charitable group (Bipolar UK) to talk to members about study and provide study and contact details to facilitator to email non-attending members

Number of individuals contacted researcher: 5
Number of potential participants who met inclusion criteria: 5

December 2014 – Study information sent via email to members of the charitable organisation via contact at Bipolar UK north-west group

Number of individuals contacted researcher: 1
Number of potential participants who met inclusion criteria: 1

December 2014 – Researcher contacted charitable organisation and charitable support group to inform them recruitment stage has ended

Appendix A

Journal of Mental Health Instructions for Authors

Aims and Scope

The Journal of Mental Health is an international forum for the latest research in the mental health field. Reaching over 65 countries, the journal reports on the best in evidence-based practice around the world and provides a channel of communication between the many disciplines involved in mental health research and practice.

The journal encourages multi-disciplinary research and welcomes contributions that have involved the users of mental health services.

The international editorial team are committed to seeking out excellent work from a range of sources and theoretical perspectives. The journal not only reflects current good practice but also aims to influence policy by reporting on innovations that challenge traditional ways of working. We are committed to publishing high-quality, thought-provoking work that will have a direct impact on service provision and clinical practice.

The Journal of Mental Health features original research papers on important developments in the treatment and care in the field of mental health. Theoretical papers, reviews and commentaries are also accepted if they contribute substantially to current knowledge.

Submissions

All submissions, including book reviews, should be made online at Journal of Mental Health's Manuscript Central site at http://mc.manuscriptcentral.com/cjmh

New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre. Please note that submissions missing reviewer suggestions are likely to be un-submitted and authors asked to add this information before resubmitting. Authors will be asked to add this information in section 4 of the on-line submission process.

Manuscripts will be dealt with by the Executive Editor. It is essential that authors pay attention to the guidelines to avoid unnecessary delays in the evaluation process.

The names of authors should not be displayed on figures, tables or footnotes to facilitate blind reviewing.

Word Count

The total word count for review articles should be no more than 6000 words. Original articles should be no more than a total of 4000 words. We do not include the abstract, tables and references in this word count. However manuscripts are limited to a maximum of 4 tables and 2 figures.

Book Reviews

All books for reviewing should be sent directly to Martin Guha, Book Reviews Editor, Information Services & Systems, Institute of Psychiatry, KCL, De Crespigny Park, PO Box 18, London, SE5 8AF.

Manuscript Style

Manuscripts should be typed double-spaced (including references), with margins of at least 2.5cm (1 inch). The cover page (uploaded separately from the main manuscript) should show the full title of the paper, a short title not exceeding 45 characters (to be used as a running title at the head of each page), the full names, the exact word length of the paper and affiliations of authors and the address where the work was carried out. The corresponding author should be identified, giving full postal address, telephone, fax number and email address if available. To expedite blind reviewing, no other pages in the manuscript should identify the authors. All pages should be numbered.

Abstracts: The first page of the main manuscript should also show the title, together with a structured abstract of no more than 200 words, using the following headings: Background, Aims, Method, Results, Conclusions, Declaration of interest. The declaration of interest should acknowledge all financial support and any financial relationship that may pose a conflict of interest. Acknowledgement of individuals should be confined to those who contributed to the article's intellectual or technical content.

Keywords: Authors will be asked to submit key words with their article, one taken from the pick-list provided to specify subject of study, and at least one other of their own choice.

Text: Follow this order when typing manuscripts: Title, Authors, Affiliations, Abstract, Keywords, Main text, Appendix, References, Figures, Tables. Footnotes should be avoided where possible. The total word count for review articles should be no more than 6000 words. Original articles should be no more than a total of 4000 words. We do not include the abstract, tables and references in this word count. Language should be in the style of the APA (see Publication Manual of the American Psychological Association, Fifth Edition, 2001).

Style and References: Manuscripts should be carefully prepared using the aforementioned Publication Manual of the American Psychological Association, and all references listed must be mentioned in the text. Within the text references should be indicated by the author's name and year of publication in parentheses, e.g. (Hodgson, 1992) or (Grey & Mathews 2000), or if there are more than two authors (Wykes et al ., 1997). Where several references are quoted consecutively, or within a single year, the order should be alphabetical within the text, e.g. (Craig, 1999; Mawson, 1992; Parry & Watts, 1989; Rachman, 1998). If more than one paper from the same author(s) a year are listed, the date should be followed by (a), (b), etc., e.g. (Marks, 1991a).

The reference list should begin on a separate page, in alphabetical order by author (showing the names of all authors), in the following standard forms, capitalisation and punctuation:
a) For journal articles (titles of journals should not be abbreviated): Grey, S.J., Price, G. & Mathews, A. (2000). Reduction of anxiety during MR imaging: A controlled trial. Magnetic Resonance Imaging, 18, 351–355. b) For books: Powell, T.J. & Enright, S.J. (1990) Anxiety and Stress management. London: Routledge c) For chapters within multi-authored books: Hodgson, R.J. & Rollnick, S. (1989) More fun less stress: How to survive in research. In G.Parry & F. Watts (Eds.), A Handbook of Skills and Methods in Mental Health Research (pp. 75–89). London:Lawrence Erlbaum.

Illustrations: should not be inserted in the text. All photographs, graphs and diagrams should be referred to as 'Figures' and should be numbered consecutively in the text in Arabic numerals (e.g. Figure 3). The appropriate position of each illustration should be indicated in the text. A list of captions for the figures should be submitted on a separate page, or caption should be entered where prompted on submission, and should make interpretation possible without reference to the text. Captions should include keys to symbols. It would help ensure greater accuracy in the reproduction of figures if the values used to generate them were supplied.

Tables: should be typed on separate pages and their approximate position in the text should be indicated. Units should appear in parentheses in the column heading but not in the body of the table. Words and numerals should be repeated on successive lines; 'ditto' or 'do' should not be used.

Proofs

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Appendix B

Excerpt of Ben’s transcript

Study: Living with a diagnosis of bipolar disorder: A narrative analysis
Interviewer: Roisin Turner
Interviewee: Ben (33 year old male)
Date of interview: 05/11/2014
Interview Length (hours:mins:seconds): 1:32:09

I:	Interviewer speaking
B:	Ben speaking
..	Short pause
…	Long pause
(0:00)	Digital audio file time marker (appears in line number column at 5 minute intervals)

Line number	Speaker		Notes
1 (0:00)	I	So, tell me about your experience of being	
2		diagnosed with bipolar disorder.	
3	B	So, er, in terms of the timeline I was diagnosed in	
4		2004 when at was the university of (name), erm	
5		and since then the erm, so since that diagnosis	
6		which was largely a gatekeeping diagnosis so um	Gatekeeping
7		it allows erm, well firstly to, for me because to	
8		explain what was happening to me at the time and	Provides explanation
9		second because until you have a certain diagnosis	
10		doctors are so loathed to provide medications that	Provides access to medication
11		are off-label, erm, and so since then, erm, so	
12		after the diagnosis itself the diagnosis was neither	After diagnosis less insignificant?
13		here nor there really, erm, apart from when you	
14		change doctors or you come across another health	
15		professional and then that diagnosis may come	Diagnosis questionned
16		into question, erm, and sometimes they’ll do that	
17		openly and sometimes they won’t, erm but since	
18		then, erm I’ve had periods where people	
19		generally when I’m well people will go, “Well you	
20		don’t have bipolar disorder, it’s more of a	

21		psychological issue", to when I'm very unwell and	Disorder (unwell) v psychological explanation (well)
22		they're like, "Well you have bipolar disorder", so	
23		my experience with diagnosis erm is one that, so	
24		once I had it and as with many things within the	
25		NHS erm in terms of mental health, once you've	
26		got it on your file it does stay there, erm but the	Diagnosis stays with you for life?
27		opinion of the diagnosis has been somewhat	
28		changeable, erm, the amount of input and debate	Differing opinions of diagnosis
29		I've had into the diagnosis has been relatively	
30		limited, erm people tend not to really give two	
31		hoots what you think apart from people that	Not heard/listened to
32		aren't in a position to diagnose, such as um	Professional's power
33		clinical psychologists um who are treating you as	Perceived differences in roles of professionals
34		opposed to erm diagnosing you, erm, the reason I	
35		say that is because I was on a trial for [redacted]	
36		with the [redacted] trial for six months with a clinical	Clinical psychologist - helper
37		psychologist called (name) and she, who I had an	
38		amazing amount of respect for, an amazing	Respect - questionning, took time
39		woman erm and she questionned my diagnosis and	
40		I fully respect her view because she took the time	
41		to spend time with me, erm, but unfortunately she	
42		has no input and in fact at one point she said,	Clinical psychologist less powerful role to help?
43		"Well what do I know, I'm just a clinical	
44		psychologist" (laughs), so er it was erm, so yea it's	
45		changeable, so that's my experience with	
46		diagnosis, so the key themes are kind of it's a	
47		gate-keeping thing so people like to wait until,	
48		they take ages to diagnose you and then when	Lengthy time to get diagnosis
49		you've got it erm it's purely so they can prescribe	For professionals: diagnosis = medication?
50		you drugs and then people will argue about	Professionals uncertainty whether 'possess' diagnosis
51		whether you have it but not really treat you, and	Lack of "treatment"
52		then um, but it often often doesn't change the	
53		way you are treated regardless because you've	

54		already had that diagnosis given to you, if that	
55		makes any sense.	
56	I	Hmm, so what was your views about diagnosis	
57		before you received it?	
58	B	Um, I think I was quite, I don’t know if this is odd,	
59		um, but er I had terrible problems with money	
60		since being a teenager, I was at (name of	
61		university) for my undergraduate degree, erm, had	
62		a really really shitty time emotionally, I mean an	Struggled emotionally prior to diagnosis
63		amazing time socially and intellectually erm, but	
64		emotionally really bad time, ended up in hospital,	
65		erm, and I had an amazing GP and she was	
66		throwing medication at me, literally throwing	Throwing medication at me
67		anything she could, she was like, you know, “We	GP wanting to help bad times stop
68		want to make this stop Ben, we want to make it	GP - helper
69		stop” and ended up seeing a psychiatrist before	
70		I was in hospital, the same psychiatrist that I saw	
71		afterwards and he said, “Nah, there’s nothing	
72		wrong with you, you’re just precocious youth”,	Invalidating Ben’s experience
73		and I thought fine fair enough, left thinking, “Bit	
74		shitty but okay”, ended up in hospital after a	
75		particularly bad period and then had to go and see	
76		him again because the way mental health services	
77		were organised in the north east it was tertiary	
78		so I had to go and see him again, at which point he	
79		goes, “I’m so sorry, I seriously got that wrong”,	Psychiatrist’s apology
80		erm and then because er, I’ve forgotten your	
81		question, sorry.	
82	I	About kind of your thoughts about..	
83	B	My thoughts, so at that point because I was there	
84		I just want it to stop and I was quite intelligent,	I just want it to stop
85		when you’re at university because, well what was	
86		Athens, is now Shibboleth you have access to loads	University - access to research
87		of journals erm so you can do more than your	
88		Wikipedia style diagnosis and you can go and have	Searching for own answers

Appendix C

Summary of Adele's narrative

Adele is a 61 year old female who was diagnosed with Bipolar Disorder (BD) 13 years ago.

Before diagnosis: *"You're not like you used to be"*
Adele shared that she has experienced trauma in her life in the form of two people she was very close to dying, her father and grandmother. She stated that, *"It never leaves you that does it, especially in those circumstances of his (her father's) death cos he died two months before I got married and he was to have walked me down aisle even though he was semi-paralysed from a stroke"*. She stated that her family was not close knit, and she is closest to her husband and daughter. Her husband experiences depression and she worried about her daughter during childhood. Her daughter was referred to see a psychologist in his first year at school because she did not talk for six months.

Adele explained that prior to her admission to hospital she attempted to take her life twice, and spent the following two years in and out of hospital. She stated that after this it was, *"Bearable, it was if anything on the high side of normality as it were"*. Only then she realised that she had been feeling depressed previously: *"It was obviously depression cos it just wasn't normal, because I've lost touch with normality really, even when I was stable people would say, 'You're not like you used to be'"*.

At time of diagnosis: *"Nobody explored whether that had affected me"*
Adele stated that she was not told about her diagnosis but read it upside down on a form: *"It'd be a form with my name on and everything and at the top I read bipolar disorder and I said, I must have thought, 'Well if it's a disorder is that what's wrong with me?' and she sort of, 'Oh did you not know?'"*. She said that, *"They explained what it was, you know, about the highs and the lows… I've been stable for so long it's not been an ongoing discussion about it all the time"*. Adele said that when her diagnosis was first discussed she was most interested in, *"Why I'd got it out of the blue like that, the only thing I could tie it down to was being menopausal"*. She said that she asked a psychiatrist whether her mental health difficulties could have been triggered by this and she was told it can happen: *"So there's no certainty about it which if I could pin it down to that it would be easier for me to accept really, or if it could be pinned down to trauma like I've had cos I've had deaths in the family that have been very traumatic under the circumstances"*. She stated, *"Nobody explored whether that (the deaths) had affected me"*, and later stated, *"They never talked about childhood, trauma from my life… a lot can happen in 47 years to have built up to that"*. Adele said that she does a lot of her own research regarding bipolar and has learnt more about it herself through the internet.

Main reflections since diagnosis:
"The person I thought I was disappeared forever"
Adele stated that the diagnosis, *"Gave me a sort of soapbox as it were to inform other people… if I ever met anybody I'm not shy about telling them what's wrong with me or explaining something weird I've done"*. She continued: *"People have said that they're incredibly astonished by how open I am, say things like having attempted suicide but it's because it has made me more aware of the fact that it shouldn't be hidden away, it should be talked about like how they talk about

cancer now… but mental health is still pushed under the carpet". Adele went on to say that that is, *"Something you don't talk about, but it wasn't my fault, I didn't do anything to get it"*. She stated that even though people may have the same diagnosis, they will experience it differently, and explained it as a globe in which the north pole represents times when manic, and the south pole represents times when a person is feeling depressed.

Adele questionned why she could not return to the person she used to be: *"Why can't I have my normality, I don't have a normality now, I can only talk about stability rather than normality… stability to me means being able to carry on with life in a sufficiently easy way instead of finding everything difficult"*.

"It's like a sword hanging from the ceiling"

Adele talked about the extremes of depression and mania: *"The sword of Damocles, it's like a sword hanging from the ceiling above this bloke called Damocles waiting to drop and you don't know when, it's like that, and that's probably how I feel in the depressed state, whereas that sword isn't anywhere to be felt when I'm on a high"*. She stated that she preferred to be in this second state: *"People seem to think I'm the life and soul of the party… I can enjoy life, people find me more enjoyable, they gravitate towards you"*.

"It's my life"

Adele used diaries as a way of remembering her experiences and would write in these when she was experiencing psychosis. In these diaries she had mentioned songs written by Jimi Hendix ('Manic depression' excerpt):

Manic Depression's touching my soul,
I know what I want,
but I just don't know how to go about getting it.

and Billy Joel ('I go to extremes' excerpt):

Darling I don't know why I go to extremes,
Too high or too low there ain't no in-betweens,
And if I stand or I fall,
It's all or nothing at all,
Darling I don't know why I go to extremes.

These songs appear to have resonated with her because she wrote about these before she was diagnosed with BD: *"Maybe I didn't realise at the time that I had written about that in this book cos I was off my trolley as we say"*. She stated that the diaries were very important to her and when she cannot remember she reads them: *"It's my life"*. She was inspired to start writing a diary after reading 'The diary of Anne Frank': *"That influenced me a lot in everything, the way I feel about things, you know, about racial prejudice and things like that, war, politics"*.

"We're all shaped by what happens from day one, it's not sort of pre-programmed in us"

Adele explained her mental health difficulties by saying, *"The brain's going haywire"*. She said that the explanation she received when given the diagnosis was, *"Chemical imbalances were mentioned, that's why I'm given chemicals in a way to rebalance myself and that's why it's a sort of balancing game, you know, one goes down and the other has be brought down to level it"*. Adele also reflected whether her previous experiences may have shaped her behaviour which may conflict with a medical model approach: *"We're all shaped by what happens from day one, it's not sort of pre-programmed in us"*. She gave an example of people committing crimes: *"I'm thinking, 'What led that person to be like that?', not that they've consciously decided they want to be like that"*. Adele appeared to be uncertain about some diagnosis decisions following her own diagnosis, *"Sometimes you think people have been given the wrong diagnosis or the actual physical cause may not have been looked into"*.

Summary of Alice's narrative

Alice is a 58 year old female who was diagnosed with Bipolar Disorder (BD) 10 years ago.

Before diagnosis: *"I began to feel as though I was sort of invincible"*
Alice described her teenage years as *"quite dark"*, but did not disclose further what this phase of her life involved. She trained and worked as a nurse for a number of years, and is married with children. Alice shared events leading up to her diagnosis of BD: *"I'd had quite a stressful time I suppose, more stressful than normal with work and er family things, my sons have both left home um, there was a bit of strain in the marriage but particularly with work I think but normally when I got stressed like that I used to sort of just worry about it but during this particular instance I started to take a lot of exercise to take my mind off it and stop eating really and got, lost a lot of weight, but along with that, along with er weight loss and doing all the exercise I began to feel quite overly well, if you know what I mean, in a way that I've never felt before and that feeling increased as the days and weeks went on until I felt that nothing could go wrong anymore, I stopped worrying… and so I began to feel as though I was sort of invincible and that I could do anything, I had so much energy that I couldn't work it off and I gave a lot, I spent more money than usual but not so much as to get into any sort of debt but I did give quite a lot of money away to charities, now that I look back I was very generous and free with my time and I felt I was so, such good company to be with, whether I was or not I don't know (laughs), perhaps I was I was a pain in the neck (laughs), but um I always felt like, I went out a lot at that time and drank quite a bit, talked a lot and laughed a lot, um, and just felt like I could a party couldn't start without me there, and really I used to really literally think that and think, 'Well I'll have to go soon and get there because otherwise everybody's going to be miserable without me' (laughs)".*

"Nobody at work really noticed because they don't at work do they, if you're working twice as hard as normal then they're not bothered really are they (laughs), so although I was losing more weight, my husband noticed but again because I was such a good mood you know it didn't really worry him all that often and I have to say I was a lot keener on sex than I normally was so you know, erm, but it was losing a lot of weight that concerned my husband so um, really to cut a long story short I had anorexia nervosa and it was that that was diagnosed but then when I went into hospital the consultant there said that he thought because of my behaviour pattern um and the way that I behaved in hospital that he thought that I had bipolar". Alice was then referred to a psychiatrist who gave her the BD diagnosis.

At time of diagnosis: *"I was a bit disappointed really"*
Alice described how she felt when she received her diagnosis: *"I'm not sure really because I was in hospital anyway and so when you're in that situation I suppose nothing shocks you really all that much because you're, you're not in a good place anyway you know, to receive things so I think the way I was things sort of went over my head really, um, so I supposed it explained things but I was a bit disappointed really because it meant I had two diagnoses to keep me in hospital really and I didn't know anything about bipolar, I mean I don't think I'd even heard the expression because it was called manic depression and that always went sort of hand in hand with schizophrenia in my mind".*

Alice went on to say that it would have been more difficult if she had received the diagnosis as an outpatient: *"I suppose if I'd been at home I would have been more worried about it because somebody would tell you that you've got bipolar and then however well they tried to explain it and reassure you in what was going to happen and stuff, as an outpatient you've still got to come home and think what's it going to mean for the rest of my life, sort of thing, and look it up on the internet and, sort of have life made more difficult for you whereas in hospital everything's taken out of your hands anyway so I had a long time because I was in hospital a long time so I'd had a long time to sort of come to terms with it really and to find out about it more from professionals that were sort of with me all the time… by the time I came out after a year I suppose I knew enough and I'd met enough people with it as well and seen two consultants about it that I was sort of okay with it by then, and I was on medication although I still wasn't well I was much better than I had been in hospital, perhaps I was a bit oversedated I think".*

"Perhaps I just felt like I was getting an explanation for what was going on, so in a way I suppose it was quite, quite reassuring in a way that something was happening that wasn't right and wasn't healthy, and that having bipolar was a way of erm you know explaining it and getting to the bottom of it as well because I suppose if I hadn't had treatment for bipolar then the eating disorder wouldn't have gone away".

"I suppose I was quite relieved really because I didn't want him to say, 'Oh no you haven't got bipolar', and then be back to square one, to have some sort of proper erm help with knowing what it was so, and I was already taking medication anyway, that was tweaked a bit so, yea it was a gradual diagnosis and I suppose that helped really, and just, suddenly being told this is what it is especially while um perhaps in a very manic or very depressed part of an illness when you can't really sort of take that information in, but I was already in a sort of um, caring environment anyway so, there was opportunities to talk about it, I can't really remember talking about it to be honest, but I must have had opportunity to, the staff must, did explain it as time went on and you know a bit at a time".

"The messages I got were it wasn't something to be taken lightly, um, but on the other hand you know was well known and well researched and you know that there were treatments for it, erm, I think the message was it was a good thing to know about and then professionals um would know how to treat and respond to you… it was a significant um diagnosis and that I would always have to be aware of it… that I wouldn't necessarily take medication for the rest of my life but I would have to take it for an appreciable length of time and have it monitored… the other messages were that it could fluctuate, you know that, um, it could be a bit unpredictable especially if my medication wasn't right… that it was going to be something life-long".

Main reflections since diagnosis:

For Alice it appeared that the diagnosis impacted on how she perceived herself and instilled feelings of inadequacy, shame and guilt:

"Taken away my self confidence"

"Having bipolar itself had sort of shut doors to me really, that it had spoilt things". Alice gave the example of employment and being unable to work made her feel guilty for a long time. *"I just felt it took so much of my confidence away in the end over time.. and it was that sort of lack of confidence that.. it had an impact really but I don't know if it came directly from having bipolar or it was a*

long time in hospital or, or any of those things but I think it probably is an attitude to bipolar that it spoilt a lot of things".

Alice thinks other perceive her as less capable, vulnerable and less robust, and perhaps her loss in confidence has impacted on how she thinks others see her: *"For it to have not affected my family as it had, although perhaps that's only a feeling I've, perhaps I feel that more than perhaps they do".*

"Feeling so inadequate"
"It was only in like a space of two years from working really hard and on top of my job and everything else at home, although I increasingly got not on top of those things which is what led to not eating and getting manic but, to, you know, feeling so inadequate really I suppose over about a space of two years".

"I don't know if it's part of my life that I'm ashamed of"
"I don't tell people that I'm bipolar.. cos they don't need to know really, I don't think, except my husband and children but I haven't told nobody else that I was, my dad doesn't know, I can't even remember telling my sister, I think she does know, I think I must of told her some reason for that I was in hospital all that time but it's nothing that discussed really cos I don't really think that it needs to be now so, and I don't know if it's part of my life that I'm ashamed of or just that I feel isn't relevant to talk about to other people if I haven't got any direct problems with it".

"It has made me feel guilty"
"Most of the the time I don't really think of bipolar as such until the topic comes up or I go to bipolar support group, it's more the feelings of being disappointed in myself really which, you know, if I hadn't had that episode and gone into hospital and things… sometimes I think would I have felt like this anyway and I use bipolar as an excuse.. it has made me feel guilty you know.. and so I feel that I should have been able to prevent it".

"The negative bit is you know like the before and after type feeling of life"
"I suppose a bit like bipolar itself really in that there's two halves to it, and part of it is you know that it's a positive thing to have a diagnosis because there's something to work with, you know that there is some understanding there and it is sort of a bit neatened up sort of thing and named so that's a positive bit in a nutshell but the negative bit is you know like the before and after type feeling of life you know, um, and that's the downside".

Summary of Ben's narrative

Ben is a 33 year old male who was diagnosed with Bipolar Disorder (BD) 10 years ago.

Before diagnosis: *"I just went off the rails completely"*
Ben shared his experiences of difficult relationships and events in his life from childhood and prior to his diagnosis of bipolar disorder which included his parent's ill-health, family loss, end of a relationship and feelings of isolation: *"My parents weren't a source of support for me… so I was on my own… then I went to university, so much support, overwhelming support, I had a family there… and then I left that family, moving away from university was terrible, it was horrible, it was wrenching".*

Ben described his fight in pushing for a diagnosis and how he persuaded a university student support officer to come to his appointment with the psychiatrist: *"I asked, 'Can you come with me because really I don't think they believe me that's there's something wrong with me'… and I can remember walking away from the consultation with her erm and I can remember her saying, 'I don't know why you're searching for a diagnosis, if I were you I would not be looking for any label at all', but that's the kind of the difficulty in terms of how drugs are licensed and how certain therapies are available to you, and how seriously you're treated within healthcare situations, without a certain diagnosis, if you don't have a diagnosis at all you're left in limbo, nothing, access to nothing, erm but if you have a diagnosis there's the potential for further care, um, and it wasn't that I was looking to be, I didn't want to be tranquilised, I didn't want to be you know anaesthetised against life or what have you, but I did want to have a better experience of life".*

At time of diagnosis: *"He had to start the consultation with an apology"*
Ben described his diagnosis as serving two main purposes at the time which were providing an explanation for what was happening to him, and as a way of gaining access to medication. He ideally would have been given access to medication without needing to *"fit in a box"* of diagnosis, however it was a necessity because he was unable to get a prescription from his GP without the diagnosis. Ben stated that he wanted to provide a quality of life for himself and it appeared that this was the only option presented to him. He described relationships with psychiatrists as being less helpful and they appeared to invalidate his experiences, disregard his opinion, and not take time to listen. He described his interaction with the psychiatrist: *"He said, 'Nah, there's nothing wrong with you, you're just precocious youth, and I thought, 'Fine fair enough', left thinking, 'Bit shitty but okay', ended up in hospital after a particularly bad period and then had to go and see him again… at which point he goes, 'I'm so sorry, I seriously got that wrong'… it was a bit little too late".* Ben went on to say, *"He had to start the consultation with an apology which was never going to end well with a psychiatrist… which was really rare for someone with mental health issues to be in quite a position of power when you're in a diagnostic or even in a clinical situation because often you don't have a great deal of power".*

At the time of diagnosis Ben said that he was provided with very little information, and consequently spent time researching the diagnosis and medication himself: *"It was never really explained to me about the difference between hypomania and hypermania, he wasn't overly worried about whether or not I'd had an episode, I think he used the fact, 'Oh you've been in hospital, I think we'll take that as a* *given'"*. Initially his diagnosis provided him with a degree of power, control and hope; these curtailed over time and his view of his diagnosis became more negative: *"I didn't expect a pillar of light to shine down and I'd suddenly get better, I know who I am, but, yea, it was kind of anticlimactic"*.

Ben spoke about people who played a role in both his diagnosis and as support through his journey since diagnosis. He shared having tremendous support from some *"awesome"* people, who included GP's, student support officers and clinical psychologists, and appeared to have great respect for these sources of support: *"I had an amazing amount of respect for (clinical psychologist), an amazing woman erm and she questioned my diagnosis and I fully respect her view because she took the time to spend time with me, erm, but unfortunately she has no input"*. These individuals provided him with time, they listened to him, and it seemed they were highly motivated to and believed in helping to make things better for Ben.

<u>Main reflections since diagnosis:</u>

"Sometimes that card can be accepted or be declined"

After receiving the diagnosis Ben experienced his diagnosis as both as *"shackle"* in terms of being limiting for example with employment and travel, but also a *"passport"* in that it opened access to medication, psychological input and support. He described it as a card: *"Sometimes that card can be accepted or be declined"*, depending on where you want to use the card. Ben stated that the diagnosis is permanent and even though there are periods when he feels well he cannot escape the diagnosis. He said that his relationship with his diagnosis is *"schizophrenic"* and explained that when he is well he is more likely to reject it, and when feeling unwell he feels it can explain his emotions. He went onto say that he reflects more about his diagnosis and it's implications when he feels well: *"Whether or not I still have bipolar disorder, as I say it's been debatable, I mean I'm in a period of when I'm unwell at the moment I can say, 'Yea, I think I am, I do have bipolar disorder', but then I can, there's other times when I'm well and I'm like, 'Nah, I'm pretty sure I don't'"*.

"You can find solace in it at times… but"

Ben stated that he did not identify himself as someone with bipolar disorder, and although the diagnosis can be harrowing it can provide solace at times: *"You can find solace in it at times as a way of explaining the shittiness of the world or maybe the shitty experience of the world at the time but then on the other side of things er it can be, the knowledge that it will probably never go away because it's not something that people tend to grow out of, the knowledge erm, er, that it can get far far worse than it is now, erm, er it can be so quite harrowing how I see myself"*.

"Telling people you're gay that's really fucking easy in comparison"

Ben thought that professionals based decisions on an identity formulated through the diagnosis, rather than considering his subjective experiences: *"Because I wasn't turning up in tears and because I wasn't having to be brought to her (psychiatrist) by the police she was really like, 'There's nothing I can do to help you, nothing"', and so unless you exhibit symptoms that they can tangibly look at erm rather than the subjective experience that you're relaying to them sometimes they can find that difficult, erm, well no, they don't find them difficult they just don't take time"*. This was the opposite experience he had with friends who focused on his emotional experience and he found this very supportive. In terms of disclosing his diagnosis, Ben felt that this was easier with people whom he trusted, but could also use this as a way to keep people at a distance. He stated that it was easier disclosing to other people that he was gay because this felt more accepted in society rather than having a mental health difficulty, which he found induced fear in others.

"Diagnosis itself is a paper-based and labelling exercise"
Over time Ben has become more aware of the philosophical debates regarding diagnosis, and has experienced differences of opinion amongst professionals. He reflected whether society is being anaesthetised by the use pharmacological drugs, and how mental health difficulties are socially constructed. He stated that his positive views regarding diagnosis may be influenced by his view of medical professionals: *"I suppose that says a lot about me in terms of how much kind of precedence and primacy I place on the judgement of medical professionals on me and their ability to judge me as a person of a certain type, erm, which I've not thought about before"*.

"Trying to save a quality of life"
Ben shared that diagnosis currently offers a level of help at the moment, stating it is, *"What I have to do right now"*, and described a 'Catch-22' situation of accessing help: *"GP was like… 'I can't prescribe it unless I've got permission from a psychiatrist to do that, and the psychiatrist can't do that unless you've got a diagnosis', erm so it's kind of led up to me just trying to save my life really which sounds really melodramatic but I mean that in a kind of panacea of saving your life which is not just kind of the immediacy of it but just actually trying to save a quality of life"*. Ben stated he would prefer access to psychological therapies but deduced that medication was the cheapest option for the NHS and therefore the main option provided to service users. Ben also stated: *"I would also take a much er greater view of clinical psychologists in terms of diagnosis, people that have actually got the ability to talk to others and spend time with others, um and can actually make practical social suggestions for care rather than just a pill um, yea, and anything that's in the DSM be it 4 or 5 does tend to be treated more pharmacologically than psychologically"*.

Summary of Claire's narrative

Claire is a 35 year old female who was diagnosed with Bipolar Disorder (BD) 15 years ago.

Before diagnosis: *"The stuff about my dad was huge"*
Claire shared that her father committed suicide when she was 14 years: *"The stuff about my dad was huge… I would be in this kind of, 'He didn't love', all these kinds of issues would come up when I was ill"*. Prior to this point she was doing well at school, but as a teenager she experienced periods of depression and was prescribed anti-depressants. Claire completed her first year at university and went abroad to do a summer job: *"It hadn't worked out so I'd come back and I'd been very low, so that was all leading up to then going back into my second year at university, so I'd gone from the low to high"*. It was in her second year that she experienced her first manic episode, and was admitted to hospital when she was given her diagnosis. Claire appeared to blame herself for her hospitalisation: *"I spent a lot of the next year regretting and thinking, 'If I'd just not let that happen then I'd still be at uni'"*.

At time of diagnosis: *"I was going to have to learn to live with it"*
Claire was initially diagnosed with Manic Depression, which she thought described her experiences more accurately than the term BD, however the term 'bipolar' was less stigmatising. Claire spent six weeks in hospital on an assessment section: *"That's where that then became my diagnosis"*. Claire stated that her diagnosis was made by the psychiatrist but, *"I can't remember somebody actually being in that meeting and being told 'this is your diagnosis', I don't remember that exact moment"*. She went on to say, *"I was so unwell that I wouldn't have been able to take on board any of that kind of side of it"*, and, *"When you're first diagnosed there's all this psychoeducation that gets kind of rammed down your throat about what it means to have that label… the comparison is always made with diabetes and people taking insulin, that was the thing that was kind of really given to me"*. Claire stated that a separate meeting with her family took place to discuss the diagnosis and medication.

At the time of diagnosis Claire said she was, *"Just trying to get your head round what all that really meant, whereas I think over time it becomes something that's like a smaller part of your life, and maybe a smaller part of how you manage things, because I think certainly when I was first diagnosed I think I wouldn't have a day where I didn't wake up and think 'Oh my goodness I've got bipolar, I've got to manage this'… so it's a thing that over time and over the course of you living with it, that's where it changes as well"*. Part of her hoped that her first hospital admission was a one-off: *"I was going to have to learn to live with it, and you know it wasn't just this blip if I'd made you know different choices or done different things that I wouldn't have ended up in that situation, erm, no it was much more kind of I'm going to have to get my head around this… the second time it was much more about acknowledging that that was it really"*. This gives a sense that Claire felt she had lost hope and perhaps her battle against the difficulties she was facing.

Claire reflected that: *"When I was given the diagnosis I was sat down by the psychiatrist and told, I suppose maybe it was laid on a bit too thick but the whole serious mental illness, you know, you're going to need life long support… I would be sitting on the ward thinking god these people should have more hope than what they're being given"*. She thought that the recovery model gives a different message: *"It's changed from telling people it's a serious mental illness, life-long illness to you've got this… you're gonna get to recovery and we're going to discharge you and then you're going to be kind of left really"*.

Main reflections since diagnosis:

"You limit parts of your life"

Claire acknowledged later in the interview that she had experienced a lot of loss such as her father, and since her diagnosis her expected university and work trajectory: *"You try and rebuild you life, but, um, yea I mean it was a huge thing, I lost my university career basically and it took me all of my 20's to get my degree… but it took a long time whereas my friends from school and then friends from university had kind of jumped through those hoops and were on the road to, so yea, that was the ultimate price that I paid at that time"*. She later explained that when she feels low she is regretful of those missed opportunities and perhaps there is some resentment that she was not able to meet those milestones at the times she expected to and how she consequently lost friendships: *"It had completely set me apart from my peer group"*. Claire also talked about feeling strong resentment towards her peers and her younger siblings in particular who also have experienced mental health difficulties but passed milestones before her. She also talked about how, *"you limit parts of your life"* and feeling agrieved and bitter by this, for example, delaying becoming a parent and how medication can impact on pregnancy.

"What makes it that one step beyond?"

Claire wondered what made behaviour a symptom of the diagnosis: *"I went on a walk with (name of friend) and we ended up singing Queen to the top of our voices, is that that unusual, but at that point something had crossed over… what makes it that one step beyond?"*. Claire went on to say: *"When you're ill you aren't somebody different you are an extension of yourself, and that's hard to come to terms with… but it is you, it's just one step beyond, particularly the manic stuff and that can be quite uncomfortable, I think that's the hardest thing to come to terms with.. which then feeds into the lows because you're regretful about what happened"*.

Claire appeared to be questionning how she was perceived by others and whether this was an accurate portrayl of her difficulties: *"When the diagnosis was made the biggest thing was coping with the drugs that I'd been given cos I was put on Haloperidol one of the really old anti-psychotics and had terrible side- effects from it, you know, couldn't sit still, which obviously then makes you look more manic"*. Claire gave examples of her behaviours that she considered normal but were used as evidence for her diagnosis: *"If you say some of those symptoms to people it just sounds well that's not so far out of the ordinary is it, and it's like you put them all together, and like for example saying about I was wearing a short skirt and being flirtateous well, so what… or like talking too much… that was one of the biggest hardest things for me cos I consider myself quite a chatty person"*.

"You think, 'God I've been labelled' and that's part of the thing I hated"

Claire talked about being given a label from the diagnosis and the difficulties with this: *"I think if you don't get that diagnosis and you end up having to struggle through erm.. yea, I don't know it's hard though isn't it because then you think, 'God I've been labelled' and that's part of the thing I hated so it's really hard, it's a toss up between the two because it kind of gives you an access point doesn't it into receiving support and that's the positive thing but for a long time yea it was* *having that label over your head and I suppose it's still, I put that label over my head, erm, which probably isn't always helpful".*

Claire talked about the words BD and how the focus seems to be on the negative aspects of a person: *"Even that thing that it's a disorder isn't it, that's the biggest thing, I mean bipolar disorder, that does kind of give a really negative thing to it, because you know, that dysfunctionalness whereas I don't think I am a dysfunctional person in a lot of ways, like the things that, you know, I've achieved, the friendships I've had, you know… evidence for and against but I think that is the trouble, a diagnosis does seem dysfunctional and disordered rather than… and it's always about the negatives a lot of the time".*

There wasn't a lot of hope given around it"

Claire talked about how her diagnosis was made: *"What made it easier for them to make that diagnosis was there was family history of bipolar in my family through my dad and my dad's mum, you know that's another thing that they lump in straightaway and go, 'Well you had all this depression and this is definitely a manic episode and then you've got this genetic disposition', so that was then it's quite easy for them to say, 'This is your diagnosis' than if there wasn't those other things".* In terms of what she would change about the message she received at diagnosis Claire reflected: *"Well certainly, I think looking back now, a bit more hope because there wasn't a lot of hope given around it".*

Summary of Joy's narrative

Joy is a 47 year old female who was diagnosed with Bipolar Disoder (BD) nine years ago.

Before diagnosis: ***"I was fractured inside"***
Joy described herself as a hypersensitive person, saying that *"people aren't just like that"*, however then went on to disclose details that may have increased her vulnerability to this sensitivity. Joy had been sexually abused by a neighbour as a child and reflected on this: *"Once the crack was cracked I could never get it back… so I always had that vulnerability, that fragility in me… I always knew I wasn't like other people, and then another major part of cracking would be I've always known I was gay but in a white hyper calvernistic conservative society that was a no-no"*. Joy described feeling that she was, *"just bad and naughty and irresponsible"* and, *"I mustn't tell anyone about it, not even acknowledge it"*.

Joy was initially diagnosed with Borderline Personality Disorder (BPD), although she was never told this and read it in her notes years later. The psychiatrist who diagnosed BD explained that, *"It's a common mistake"*. Although Joy was not aware of her BPD disgnosis she was given access to counselling and psychotherapy, whereas she reflected if she had been given a diagnosis of BD: *"They would have just given me pills and left me to go home"*. Joy did say however that a diagnosis of BPD has *"terrible connotations"*, whereas BD does not, but later goes on to say that having a diagnosis still provides a label and stigma: *"People still think that it's, that I'm mad, that I'm going to hurt them"*.

At time of diagnosis: ***"I was right, there was something abnormally wrong with me"***
At that time of her BD diagnosis Joy was in hospital and hadn't slept for months, describing herself as, *"Mad as a hatter"*, and in a, *"Really bad mixed state"*. Joy described the trigger as an aggressive take-over by another company at work, which increased her anxiety meaning that her sleep was severely impacted. Joy appears to minimise the impact of this experience saying, *"It was just plain simple normal life that I couldn't handle"*.

Joy talked about the positive experience she had with the psychiatrist: *"The psychiatrist knew exactly what she was doing, she explained it to me really well, her sister had it so she said, 'Take your pills, stop drinking, and you'll be fine', and she was really keen to tell me to go and look into it, to research it, to find my own ways erm, and that it wasn't a terribly bad horrible thing um, she told me that her sister was a QC and so I had her kind of positive spin on it, she was a really old um very eccentric locum psychiatrist, I was very lucky to get her"*.

Joy described her diagnosis of BD as, *"Such a relief because I was right, there was something abnormally wrong with me"*. She said that it gave her access to NICE guidelines, access to secondary care mental health services and professional support which she finds invaluable. Throughout the interview Joy used the terms disease, sick and illness to explain her diagnosis, and stated that she experienced relief because, *"People can manage diseases… it was a relief to know that I wasn't just being bad or irresponsible, that I had reasons"*.

Main reflections since diagnosis:
"I don't want to be a fixed-sick person"

Joy also talked about identity and stated, *"I don't want to be a fixed-sick person, I want to be a well person and enjoy life otherwise I'm not going to bother to live it"*. She stated that, *"I don't use it as an excuse, I use it as a responsibility that I need to take in order to make my life better"*. Joy said that she had never spoken to her family about her feelings and what she was experiencing. She thought that having a diagnosis would help them gain an insight into what she was going through although is not sure whether they have researched the diagnosis.

"I'd rather tell somebody that I'd a drinking problem"

Joy stated that, *"I'd rather tell somebody that I'd a drinking problem rather than them know I've got bipolar, isn't that interesting… I feel more ashamed about having that than being an alcoholic, how awful is that"*.

"The medical model is devastating"

Joy talked about the medical model does not help her, and she prefers a recovery model of care: *"The medical model is devastating… the medical model rights you off as ill, unfixable, and that you're kind of dysfunctional and will stay dysfunctional… that's not very helpful"*. She later stated that, *"The medical model concentrated on my illness… it concentrates on medication to fix it, once they've done that they can move on, that's all they do… sometimes I need help building resiliency in my life and a medical model doesn't do that"*.

Summary of Kim's narrative

Kim is a 55 year old female who was diagnosed with Bipolar Disorder (BD) 31 years ago.

Before diagnosis: ***"I always wondered why my mother destroyed me"***
Kim stated that the most traumatic time of her life was when she experienced agrophobia whilat in her last year at primary school and this made her feel very low. She said that she was also missing her twin brother because he went to an all-boys school. She described how she tried to cope with this as a "schizoid defence" as she said Van Gogh experienced; *" Van Gogh, yea, he went into a schizoid defence and that's the best way I could describe it, I couldn't cope with all this phobias and fears and missing my twin brother, so I went into a um like a schizoid defence, and as soon as I did that that's when the mania started, um, and nobody's looked at that… I couldn't explain it to anybody because I was too young to explain it, I just wanted to die cos I couldn't deal with it, it was too frightening to deal with and then everything got into a mess, but when I say got into a schizoid defence that's the easiest way I could describe it"*. She felt ignored by her family and teachers at school and described her pre-16 school days as *"dreadful"*. Kim shared that her relationship with her mother was difficult; she said her father did not let her see an educational psychologist and she became extremely withdrawn. She stated: *"My mother who er who eventually destroyed me um, cos she just yelled at me and tore into me all the time, um, I think if, I think no even if she was told the diagnosis she'd still react like that cos it's the way she functions apparently but, um, er, well I'd hope to be treated more sympathetically"*.

When she was older Kim asked to see a psychiatrist but she was referred to a clinical psychologist. When she moved she asked her new GP if she could see a clinical psychologist and she spent five years with her until Kim moved again. Kim described her relationship with this clinical psychologist: *"She was like my second mother, she was like trying to give me approval… but this time was very very important to me… and that's different because she didn't suggest, 'Oh I think I'd better refer you to a psychiatrist, you need medication, you need hospitalisation' or any of that"*. She talked about having a close relationship with a male who, *"Was a bit like a Rufus May, he'd been in hospital for three years himself when he had ECT and um lithium, and I think he decided that no I didn't need any of that, er he was going to take care of me and um which he did and um for a year he looked after me, he got me over the depressive part and then the elevated part as well, um, and it was quite something… so he looked after me but all the time I kept seeing a clinical psychologist erm, er, so that was important because if I hadn't seen the clinical psychologist it might have been harder"*. Following her next move she again asked her new GP to be referred to see a clinical psychologist, however he referred her to see a psychiatrist who gave her the BD diagnosis.

At time of diagnosis: ***"When you think about it he'd only met me what five ten minutes"***
Kim stated that she felt relief when she received her diagnosis; she said she was fed up thinking there was something wrong her and not being taken seriously and dismissed. This was brought up at numerous points throughout the interview and demonstrated how important this was to her: *"I'm so fed up after 31 years of not being understood and disregarded"*. She said that the psychiatrist was, *"extremely puzzled, extremely worried and extremely perplexed"* when she met him because she had not been in hospital and, *"he was thinking how on earth did I cope"*. She

said that, *"I found it very difficult to a psychiatrist after talking to a psychologist because to me psychiatrists haven't got people skills"*. She said that he asked her questions but did not really explain anything to her, and said regarding the diagnosis he made: *"When you think about it he'd only met me what five ten minutes, so it's not because he's known me, he hasn't seen me"*.

Kim stated that the diagnosis, although provided some acknowledgement of her difficulties, did not influence intervention from services: *"I knew there was something seriously wrong and it hadn't been properly acknowledged and when it was that felt really er, that felt really good, um, but other than that I don't think anything else um, I mean the irony of it is the help I got before the diagnosis was better than I had after the diagnosis so (laughs), so er, so apart from just somebody else actually acknowledging it um I don't think anything else really improved from the services cos I was already getting the sort of best help, what I perceived the best help er before I was diagnosed anyway"*.

Main reflections since diagnosis:

"Maybe that was my miracle"

Kim talked about her faith and how this has kept her strong: *"I am an Christian and I do believe in miracles and maybe that was my miracle… because it's my faith that um has kept me strong as well, and how god's given me miracles and I really know my god's gonna help me"*. Her miracle was meeting her "Rufus May" character who provided her with acceptance and support.

"It helps you to be more gentle with yourself"

When asked about the positive aspects of having a diagnosis Kim stated: *"I think it's um my self-worth because I think if I hadn't had a diagnosis I'd be thinking well, um, you know, 'Why can't I do certain things, why can't I hold a job down, and why can't', you know, it helps you to be more gentle with yourself because you realise that you have got a very serious condition, erm, erm, so, er, yes and I think helps you to erm access therapies better and you've got a better understanding of yourself and I think personally the self-help groups are an absolute er, mine in a erm, salt mines, you know, they're just, you get so much support and understanding and you learn so much more about it from there"*.

"It sounds too good to be true"

Kim described her involvement with the Soteria Network and how important this has been in helping her manage her difficulties: *"I'm so glad that there is an organisation called Soteria where there's evidence-based that people with psychosis or people in extreme distress can get better without medication and hospitalisation, so it's like' 'Oh somebody believes me', but I think even if I did try and tell him (the psychiatrist) he, you know, um and in lots of ways it was too good to be true but I don't think people really believe it, and especially psychiatrists you know, I think he was really pleased to give me this medication because he felt that was his role and you know, he wanted to say, "Well this is what you should be taking", um, but having said that he never followed that up because lithium didn't do anything for me"*.

Kim explained how she continued this approach in her life: *"I manufactured that similar sort of thing with my er partner, so in a sense I've had like a Soteria setting at home quite a lot of the time, I sort of, if I'm in crisis I automatically go into Soteria gear… I mean that was the way that I was helped at the beginning and that's how I've continued, so the mental health services haven't really got involved and they don't seem to take me that seriously, 'Oh she's', or they* *assume that I'm a lot more well than I actually am, they don't understand what's actually going on, er, at all".*

"I've been treated more humanely by clinical psychologists"

Kim talked about her different experiences with clinical psychologists and psychiatrists: *"If I had a choice between having a clinical psychologist in a group setting erm for a long time without a diagnosis or whether to have that for a short time and have a diagnosis I prefer the former really, um, cos it would give me that um balance and um and I'm sure that's probably why I didn't end up in hospital… it's not medication that can give you the balance it's a psychological balance that you can feel inside you, er, it's like being in a raging ship, you can both be in raging ship but I can feel more calm than the other person, um, you know because they haven't had that, those psychological therapies, I can feel more calm as if the ship isn't raging, um, that's how it feels… I just think those five years with that clinical psychologist was just out of this world and wanted it to continue, and getting the diagnosis wasn't as important as that".* She later went on to say: *"With psychiatrists I just don't feel you can have a dialogue at all, so um, basically all my learning was around what (name of person) had told me and what I'd learnt in self-help groups cos I hadn't learnt anything from psychiatrists at all".*

Summary of Martin’s narrative

Martin is a 70 year old male who was diagnosed with Bipolar Disorder (BD) 7 years ago.

Before diagnosis: ***“I just kept my head down and I kept going”***
Martin did not provide a lot of detail regarding his childhood, but did state: *“I had something wrong with me when I was 17”*. Martin described exposure to sexual behaviour at a young age: *“I was introduced to that sort of behaviour when I was eight by two older lads who eventually left but er they used to, they used to get kids in the shed and er, “Let’s have a rude meeting”, and it never occurred to me that it were wrong”.*

Martin stated that: *“I’d have periods when I was very sad, sad at work which was difficult… those were bad times, um, I’d often go when I went home I’d lie down on my face on the bedroom floor and I’d cry my heart out which relieved tensions, um, on the other score there were periods where I was er absolutely full of joy and the joys of spring and erm, I suppose that er I went over the top quite a few times”.*

He spoke briefly about his relationship with his parents: *“I look on my dad’s attitude to me and somethings that happened um, me dad had a touch of it as well, a really foul temper you know, and er couldn’t get close, and a mum who was much older”.*

Martin reflected on his positive attributes, which may have also contributed to circumstances that occurred later in life: *“I always had a self-belief and an ability to er concentrate, an ability to plough on regardless of the circumstances, you know you might call it clingability, hanging to the wall, hanging you know by your fingernails and you’re not going to slide down, and I suppose these are good aspects you know of the disorder”*, and, *“I run a factory of 110 people, I held the whole bloody thing together but that’s what you can do, that’s what, people are creative, only when they’ve got this er disorder, it er gives them drive, it helps them, trouble is it gives you too much bloody drive”.*

At time of diagnosis: ***“It confirmed that there’s been something wrong with me most of my life”***
Martin stated that his daughter told him about BD, and he looked on the internet about Stephen Fry: *“I started reading it, I thought, ‘My god that’s me’, so I went straight to the doctor and poured my heart out to him”*. Martin was then referred to a psychiatrist and was given a diagnosis of BD: *“I was convinced that was what was wrong with me, and the doctor agreed, and the psychiatrist she told me to buy a book, a notebook and start writing things down, and I started and I thought, she didn’t tell me how to do it, and I decided to give myself a point system between one and six, six was high, one was devastatingly low, and I did that for what three months before I went back and she opened it and looked at it, ‘Rubbish’, I thought, ‘That’s me’ (laughs), so I’d done it all wrong… anyway um then she agreed that I’d got bipolar disorder it only confirmed it didn’t worry me at all, it was a sense of relief because it confirmed that there’s been something wrong with me most of my life and that’s why I behaved in lows and highs erm… modern medications are miraculous because in the last seven years I’ve done nowt that I shouldn’t have done… we now know what’s wrong, and you’re not a bad person, it’s erm just how your chemicals in your body have er streered you into er situations where you’re absolutely miserable or whether you’re so happy”.*

Main reflections since diagnosis:

"It keeps a lid on things"

Martin stated that it took several months to *"get the medication balanced"*, and said not he does not experience lows or highs: *"It's all in the past, it's all gone, I'm quite balanced, nearly normal'.* Martin also said the following regarding his medication: *"All I needed to do was get on top of the medication cos it's a nightmare at first, it knocks you right out"*, and,
"Thank god for modern medicines, it's allowed me to be straightened out although I can still self-indulgence now and again I've got to be careful particularly er because of the medication", and, *"It's not a dark night all the time, you will come out of it eventually and you'll have a period of stability erm, keep taking your medication otherwise if you go high it'll land you in hot water".*

"I'm afraid you might go high"

Martin described a situation when his psychiatrist wanted to increase his medication dosage: *"The erm psychiatrist wanted me to take another 200mg of Depakote… and I wanted to do what she said but I could not get on with it, I fought (inaudible) I was still falling asleep during the day and no energy and no appetite and um, I got hold of her on the phone and I told her, 'I'm not going to be taking that, it's too much, it must be wrong, I'm not getting on top of it', and er, 'Oh', she said, I said, 'Does it matter?', she said, 'Well it's just that I asked you to do that because I'm afraid you might go high', well she can be content with that because I haven't and I didn't take it anymore and I haven't gone high, well my wife might if she was sat here say, "Ah but this, ah but that, don't you remember when", but it's nothing like what it used to be like".*

"Something that's inherited, it's in your genes"

Martin talked about his diagnosis and gaining an understanding: *"Finding out what it was answered an awful lot of questions about my past life, so the diagnosis was very important because it allowed me to accept what had gone on… but then I could live it, I knew I was er ill, I needed treatment and the treatments worked"*, and *"Well it's made me understand myself, I know why I behaved in the way that I did with downs and with ups, and when I was miserable for a couple of years, I knew why I did that, why anxiety riddled my body".*

Martin also talked about how he thought BD may have impacted on other people:
*"Yea, yea because look at Irish Americans and um Italian Americans in particular, people who
emigrated from devastated lives in the mid 19th century, and jumped on a ship and just went there, although you know there's so much creativity and drive in American society particularly among these people, and it's quite likely that those who are determined to erm take all the risks that were going to do something about the life that they seem to be inheriting they, I think that um they had some form of disorder, bipolar disorder because it made them do things".*

"A lot of people who are actors and actresses and creative writers have got this thing in their blood as well, cos when it's riding on the high side you are creative, you do think um, you can work through problems and come to solutions, to answers which lead you to solutions um very quickly and you can implement change and bring people along with you".

"What gives me the right to think I know better"

Martin provided a few examples of times that demonstrated his respect for professionals and how he was reluctant to question their authority:
"I once mentioned it to the doctor I don't know about 12 months ago when I was in, and erm he said, "If it's not broke, don't fix it, stay with it", and of course I did do, didn't jib, didn't decide I was going to cut back off my own accord, I followed his instructions and um he's right, it's just a mood that um, perhaps I'm taking too much, yea, something that um you've not to listen to, comes into your mind and you've to ignore it, so I suppose that's unhelpful thinking that I know better than the medical man, woman".

"What gives me the right to think I know better about a subject which she's not only qualified in has decades of experience in cos she were knocking on, she were pushing 60, so she's seen the mental health um industry shall we call it, through her own eyes for 40 years and she will have seen how it's changed and its attitudes to people and its approaches, and the medication that's available, and a greater understanding of um these disorders so who am I to say that it would be better if we did this or it would be better if we did that, no, I can't do that".

"I don't admit to anybody that I've got a mental health issue"

Martin shared how he would prefer to tell people he had a physical health problem rather than mental health difficulty: *"Under no circumstances I don't admit to anybody that I've got a mental health issue because I do feel people don't understand it and if you've got a mental health issue you're a bit, you know, don't come too near me, so yea I suppose that's a down side but um, why should I tell them, I wouldn't tell them if I'd got, well I suppose I would, if I had cancer I suppose I would let people know I was terminally ill or that er I needed treating to get rid of it, ask them to say their prayers for me, erm, have masses said for me but erm with this I don't do that, I'm just normal as far as anyone else is concerned".*

Summary of Mary's narrative

Mary is a 51 year old female who was diagnosed with Bipolar Disorder (BD) one year ago.

Before diagnosis: ***"Too much expectation"***
Mary shared that she had a nervous breakdown at high school and experienced depression throughout her 20's: *"School would definitely be pressure, expectation, a complete loneliness, erm, I went to a Catholic Grammar School, it was horrible, erm, I think I had my first nervous breakdown there, and erm, eating disorder, when I said I've not go, I've never actually diagnosed with this but it's acknowledged, I definitely had eating disorders earlier on, the only eating disorder I've got now is I eat too much, erm, but yea, eating disorders, loneliness, pressure, erm, and just feeling out of step with everybody else"*. She stated that there were high expectations placed on her from her parents as she was the *"brainy one"*. She said they expected her to go university and she decided not to go: *"I then thought, 'Sod this' and said, 'No I'm not going, I'm not going', and then proceeded to have a baby"*. Mary then described having periods of *"debilitating depression"* and times of *"pure hedonism" and "complete over the top behaviour"*, and was hospitalised at various points during her 30's.

Mary said that she had been discharged from her current psychiatrist: *"With basically, 'This is as good as it gets""*. Mary stated that she approached her GP 18 months later after her son was diagnosed with BD and she read material about it: *"I've been diagnosed with major depressive disorder for donkeys years… I didn't know about bipolar two and it was my son was diagnosed with it and when I started reading about it it just described me, um, so I went back to my GP and I said, you know, 'I think my diagnosis is wrong, I think bipolar two is a more appropriate diagnosis', I spoke to him and he was in complete agreement with me, wrote back to my psychiatrist who, it wasn't my psychiatrist at the time, another one answered and said, 'No, there's never been any evidence of this', which was complete rubbish, and my GP was so supportive and he said, "No we're not giving up there", wrote again and it was a psychiatrist that I'd seen on an ongoing basis in the past, she saw me, said she thought there was something in what I'd said and then um I had a couple of really extensive appointments, one including my family, erm, and she said that she thought a diagnosis of bipolar two was like a more appropriate diagnosis so that was a year last November"*.

At time of diagnosis: ***"Fitting pieces of a jigsaw together"***
Mary stated that she had known her psychiatrist for many years and felt familiar and comfortable with her: *"I've got an established relationship with her, I don't feel like she talks down to me, she talks to me as an equal, she asked me my opinion, erm, she knows enough about me and I know enough about her that it's a comfortable relationship so I think that was the best case scenario to be diagnosed with somebody that you're comfortable with and you've already got a rapport with"*.

Mary was not provided with a great deal of information at the time of diagnosis about BD as it was assumed she knew because Mary herself had approached the psychiatrist about it. Mary said she was provided with a positive message regarding the availability of new medications and provided with a hope that this would make things better for her.

Mary stated that her diagnosis made sense to her: *"It made absolute sense, it described me, I can't believe that nobody picked it up either, you know, the sort of recklessness, erm, you know, the all or nothing aspect of it, all or nothing, my sister's always said to me, 'Oh you blow hot and cold', and if I do something I'll launch myself into it, reckless ridiculous behaviour over the years has just been, you know, there's been a lot of that and it just all made so much sense, it really did".* She described feeling initially relieved and optimistic: *"It was a relief initially, erm, and I just thought that it opened up, I thought things could get better from when actually erm I thought it, you know, would open up new options and hopefully onwards and upwards, but it hasn't quite been (laughs)".*

Mary later went on to say: *"I was pleased in that it was an explanation, and I was pleased that it also validated what I believed erm, upset that there'd been so many years of it not being diagnosed but sort of thought, 'Well that was then this is now, onwards and upwards sort of thing', erm, but that was quite quickly replaced by feeling very very sad and miserable about it, erm, because I thought it just sort of defines my whole personality really, erm, so yea, initially I was pleased and then that was soon replaced by sadness… it made sense of a lot of negative things and I look back at them with sadness, um, not that I could have or would have done anything different but just with the new knowledge I'm putting it, like fitting pieces of a jigsaw together, it made me sad of the ridiculousness of some things that I've done and the way that I've behaved really".*

Main reflections since diagnosis:
"It doesn't have to define me as a person"
Mary reflected that now she has, *"Hit some sort of middle ground which is unusual for me, erm, some middle ground of right well it doesn't have to define me as a person but I can now be honest, and I've spent so many years lying, I mean I'm not a pathological liar or anything but you know that sort of, 'How are you?', "Fine", and you're not fine, you know that sort of putting a face on and everything".* Mary stated that because she does not need to hide things she feels more accepted for being herself now rather than feeling criticised.

"Allowing me to be me"
Mary stated that gaining understanding and acceptance from family has been positive: *"Allowing me to be me basically".* The choice of the word *allowing* is interesting and gives the listener a sense that she wants or needs permission from others to be herself. She also states: *"I'm a hard person to love so fair play to them for sort of sticking in there really"*, which implies that she is critical towards herself. Later in the interview Mary reinforced her need to feel accepted and how she felt the diagnosis had helped with this: *"Knowing that I'm not a worthless person"*, and *"I always knew I was a bit mad and now I know why I'm a bit mad, and it's okay to be a bit mad, and I actually quite like being a bit mad (laughs)".*

Mary stated that she does worry others will think she uses her diagnosis as an excuse: *"I'm paranoid about being perceived as using my diagnosis, you know, sort of, 'Oh well you know', and you know sort of fallen back on that as an excuse, I'd never do that, but for instance erm you know in company I'll have just had enough and I'd always sort of just disappear upstairs and everybody would go mad, now everyone knows I've got get-out clauses to, you know, to not be overloaded by being around people so they accept that now, they don't just think it's me being rude, you know sort of small things like you know, things like that where people just accept me for who I am".* In terms of feeling she was understood more following her diagnosis Mary later reflected: *"No I don't think people do massively view me differently because they just thought I was a bit odd anyway".*

"I don't want it to become a self fulling prophecy"

Mary said that the diagnosis helped her understand herself better: *"It rationalised the extremes, and also one of the things about, when I'm in a really sort depressed period I'd be so angry at myself because I'd had the experience so, you know, sort of hyper spells and an insight into what it was like to be energetic and focused so I'd always beat myself up and think, "Well if I could do that then why I can't I do it now?" you know sort of when I'm virtually unable to get out of bed and just everything is black and gloomy and I want to die, you know it's like, 'Well why do I feel like this because I know I can do that?' but now it's a case of I know I can do that but it's not always within my control to be able to do it, does that make sense, er yea, I don't beat myself up as much but I don't want it to become a self fulling prophecy that you know it's okay to just go 'Urgh'".* Mary explained her manic episodes in both a positive and negative way: *"Hypomanic phases, they were phases were I just thought I felt better and I liked them but looking back now the level of sort of obsession erm obsession completely over the top with just absolutely no ability to put the brakes on myself at all"*, and, *"I always feel cheated after I've had sort of a bit of a hyper spell I always feel cheated afterwards, erm, because it's a bit of an insight into you know sort of looking forward to things, enjoying things, having energy to do things".*

Summary of Poppy's narrative

Poppy is a 56 year old female who was diagnosed with Bipolar Disorder (BD) 37 years ago.

Before diagnosis: *"The bright me, the troubled criticised me"*
Poppy stated that, *"I've always known I was different"*. She described attempting to take her life at the of 14 years and her family being dismissive: *"They put it down to situational teenage stupidity, but I knew there was real real pain and it was not do with breaking up with a boyfriend and it was not to do with not living with my parents, I knew it was really deep inside me"*. Her father was a psychiatrist who had high expectations of her, and she said, *"He always saw me as a brain without a body"*. She described her relationship with her mother as terrible and her mother as very damaging. Poppy questionned whether this relationship may have been a factor in her mental health difficulties: *"I'm not sure how much of this is because I was raised by a mum who was all huggy kissy one second to 'you're horrible, you're fat, you're ugly, no one will ever love you' kind of person, and that's enough to give you two extremes"*.

At time of diagnosis: *"Am I bipolar or do I pretend not to be?"*
When Poppy was originally diagnosed with BD the term for this diagnosis was Manic Depression. She said she saw it written down in a file before she became aware that she had been given a diagnosis, and was shocked by some of the things the psychiatrist had written about her behaviour: *"Something like sexual behaviour, I'd seen it as being normal and me being maybe flirty… so some of the things he saw as symptoms of it leading him to forming this diagnosis, um, I saw in a new light when I read the diagnosis and when I read how he described some of my behaviours"*.

Poppy described feelings of relief to have a name for something that was causing her distress and guilt lifting because this was not *"just bad behaviour"*. However she also experienced confusion due to her parent's reaction. She stated that both her parents both denied her difficulties: *"You definitely don't have a mental illness and it's definitely not bipolar or manic depression cos we know what those people look like"*. She shared that this then impacted in her access to treatment: *"I wasn't really treated by the professionals in a way that I might have been had I had parents who said, 'She is clearly very very distressed, what can we do', instead they were saying, 'Leave her alone, how dare you say she's got a mental illness, how dare you, we know her better than you, we'll sue you if you do anything'"*. Poppy stated that she would instigate accessing treatment but this would be stopped by her parents. She described her mother feeling ashamed because her daughter had a mental illness, and said she still denies it to this day. There was a feeling of hope that the diagnosis label would show her parents that there was something wrong: *"I felt saved by it a bit really… thank goodness somebody is taking me seriously, recognise the pain I'm suffering… because I've been told for so long, 'Don't be stupid'"*, but went on to say, *"I thought this was gonna be the beginning of getting better, but it wasn't as easy as that"*.

Main reflections since diagnosis:
"It means that you're not looking at the whole picture"
Poppy described the diagnosis being a helpful shorthand to say to people, *"I may have difficulties with certain things"*, however later went on to say that this can be dangerous because, *"It means that you're not looking at the whole picture"*. She said that she finds the diagnosis helpful when she is critising herself and can

use the diagnosis as a way to give herself a break: *"But I'm bipolar so it is a bit more difficult"*. She uses it as a way to ask others not to judge her by informing them of her diagnosis: *"I sometimes put it out there as a preamble to mean, 'Please don't judge me harshly if I talk too much, irritate you, what have you"*.

"Maybe it's made it slightly easier for me to blame the diagnosis, the illness, when it's something I could do something about"

Poppy thought that Stephen Fry has given the public a positive alternative view of BD: *"I'm more comfortable saying to people I was bipolar because they knew it could be a successful person not a lunatic, not someone who should be locked up in a hospital"*. Poppy however still thought that there was a stigma regarding mental health difficulties to the extent that she thought her son would prefer she had leukemia. She also said that *"Seeing it as a fixed thing about me possibly has stopped me exploring the fact that perhaps one day it won't be like this, and maybe it's made it slightly easier for me to blame the diagnosis, the illness, when it's something I could do something about"*. She later said, *"I might be able to work on myself and the aspects that cause problems easier if I didn't lump it all together and see it as this huge bipolar things which I see as probably insurmountable"*.

"It might be all we've got to get help"

Poppy talked about an assessment session she had with a psychologist who stated on their first meeting that, *"He did not believe in bipolar"*. Poppy swore on numerous occasions when she spoke about this, and it appeared to have had a great impact on her. She thought this comment was particularly unhelpful to start a discussion with, and was angry with him even though she agreed with him to a degree on an intellectual level. He did not offer an alternative way of thinking which worried her: *"Do not take away my only, it could be my only thing I'm holding onto, it's a diagnosis therefore the medication can work, I'm clinging onto this, 'I don't believe in bipolar', oh no I've got to drown then… it might be all we've got to get help… which service is going to help me without a diagnosis?"*.

"I am not loony"

Poppy stated that, *"It's not that I want the label always and cling to it"*, and went on to talk about her family being dismissive of her difficulties and impacting on how she perceived herself: *"If you would only be open to what might help that suffering, you could actually be a resource, but instead you're making us go, 'Oh my god, so I'm not bipolar, but I'm just a terrible person, I'm just badly behaved', which doesn't feel very helpful at all to me really"*. She said that support groups also help her to see that *"Oh, me too"*, and they have helped to identify non-medical ways of managing it. However she also stated that she wants to say to people, *"I'm bipolar but I do not suffer from mania, I am not loony, I'm different from those bipolars over there because they're loonies and I'm not a loony"*.

"I see this all as me"

Poppy stated being a Buddhist influences how she perceives her mental health: *"I don't believe I have a soul that's separate from me, so I do think that I'm just chemical firings going off in my brain"*. She questioned whether there was free will and whether people behave purely in response to their upbringing and environment: *"I don't know how much is caused by something we might describe as bipolar, maybe I would have always been very talkative, chattering five million things to the gallon even if I wasn't bipolar"*. She then went on to say, *"I'm always aware of what I'm doing, I might not like it and I may not be choosing really to be doing those things, I'm acting out of impulse, but I see this all as me"*.

"I myself don't know how much of it is my, which bit is my bipolar me an which is just Poppy… sometimes I will blame bipolar for something which I think is probably just me being, wanting my own way or something". She gave an example of when her husband may attribute a bad temper to her mental health, but she would think, *"No, I'm a bit of a grumpy person, I like my own way, or I might think, 'Actually no it was you, you're being an idiot (laughs) and that's what's irritating me"*.

"The side effects can be so much worse than the benefits"

Poppy talked about the medication: *"The side effects can be so much worse than the benefits, I still find life too difficult to do really, so I still want a button that you push and we all disappear"*. She later stated, *"CBT was probably the most life changing I would think even over the medication, CBT was amazing really"*.

"They can't fix this"

Poppy's father's role as a psychiatrist and seeing him rescue people in pain and distress gave her hope that she could also be *"fixed"*, *"Unfortunately since the diagnosis I had this feeling that, 'Well then they can fix it so now we know because my dad was a genius at fixing people'"*, but, *"I've been increasingly saddened by the fact that they can't fix this really, and they say they can and I've not met a single person who says they're bipolar and thinks they have been fixed"*. She likened mental health to physical health (diabetes), and said that it was disheartening that money and research is not given the same priority: *"No money is put into mental health at all, no one cares but the suffering is immeasurable"*.

"I thought it saved my life at that time"

It appears that non-medical approaches have been invaluable for Poppy, such as access to classes: *"I had woodwork classes, art classes, all for free because I was bipolar… I'm amazed by what there is if you are articulate enough, bright enough to be able to access it, or if you've got a doctor who can lead you in the right direction"*. The extent of this value to Poppy is highlighted here: *"The woodwork was cut, which was heartbreaking to me and I campaigned and protested cos I thought it saved my life at that time"*.

Summary of Sammy's narrative

Sammy is a 60 year old male who was diagnosed with Bipolar Disorder (BD) 11 years ago.

Before diagnosis: *"I'd probably been in mania for 20 years"*
Although Sammy did not talk in detail about his past experiences, he did describe the moment when something changed for him and how this led to his diagnosis: *"At that particular point I owned three accountancy practices erm and, er in, I've probably been in mania for 20 years but not realising it as you don't exactly go to your doctors, saying, "I'm feeling wonderful', erm and in February 2005 I'd gone out to see a client er, a client I'd had for 20 years and when I got there I sat down as usual, got all my papers out and suddenly realised I don't know who I was, I didn't know why I was there, I didn't know the reason er everything had just gone completely (clicked fingers) out the window, and I can't tell you why it happened it just did, and they realised I was ill, they realised I couldn't even tell you what their names were at that time, so they contacted home and had me duly sent to hospital very quickly.*

Sammy continued: *"When I got there they started down the line of Alzheimer's, dementia, perhaps that was the problem and they did all the various tests for that and when they came back clean they then started looking at the mental side and from that point onwards within a matter of weeks I was diagnosed as being suffering from deep depression of bipolar, so that was how it just led up to that particular point, um, the doctors diagnosed the fact that I'd probably been in mania for 20 years when I explained how I was able to run three practices myself, I have managers there but could not trust, nobody could do it as well as I could it, that was the way it was and the way I felt, so I used to run around every day from office to office to office and back to another office again in order to make sure the work was being done the way I wanted it to be done, and that's the way it'd been".*

At time of diagnosis: *"I just shut the door and didn't let anybody in"*
Sammy described his diagnosis experience: *"(Name of psychiatrist) said, 'You've got, we feel that you've got bipolar from what I've been told', because I didn't tell him a lot about it, it was my partner telling him how I'd been working the last 20 years, you know, doing 72 hours without sleep, just continuing on through and not even thinking about sleep, that he diagnosed that and then he put me on three different types of medications, erm in the hope of bringing me back up again, but those medications really, I don't think helped".*

"It's an imbalance of the brain which erm is probably never going to be cured unless somebody comes up with some fantastic drug at some time in the future then it's never going to be cured, it was, when I was diagnosed it was explained that it was a life-time illness".

Sammy explained how he felt about his diagnosis and how he was ashamed of it: *"It was a shock, I'd hardly ever been ill in my life, erm, the odd cold here, but tended to work through them, didn't even think about it, and and suddenly I've been diagnosed and told it was very unlikely I would work again, and when you've worked and built your businesses for 30 years that is something to be ashamed off, and I was ashamed and I withdrew".* Sammy shared that he and his ex-partner were very money orientated, and when Sammy was unable to continue making money, *"She didn't want to know and walked away".* Sammy described the next five years as being *"in the wilderness"*; he was unable to leave his house and he gambled on the internet. He was isolated due to the fact that he had been *"ostracised"* over time from his family because of his ex-partner and they were not aware he was unwell. The mental health team were concerned and threatened to section him if he did not open the door to them: *"Well if you can imagine, I'm now terrified of going out through my front door so I did open the door, let them in and shut very quickly behind them, erm, and that was my start of my road to recovery, er, she (the Community Psychiatrist Nurse, CPN) couldn't understand why there was no back-up, why I had just been left, and she contacted the family, and they were horrified".*

Main reflections since diagnosis:

"I knew there was something wrong"
"In truth if I look back over the 20 years I knew there was something wrong but I didn't know what it was, I didn't know, I knew there was, it's funny in the back of your mind you feel things are not right so by getting the diagnosis I finally found out what the problem is, and once you know what the problem is you can start to do something about it… it took me longer because I was ashamed of it".

"Medication can zombify you if you're not careful"
"I think people get over medicated, I think psychiatrists have an attitude of, 'Let's keep them down', and that's what tends to happen, I have seen so many people come through the doors of our meetings who are what I would term zombified because the medication is keeping them there, you know some people do go too high and they have to be medicated to a certain level, but when someone walks through the door and tells me they're on six different types of medication, that's wrong, er so, these are areas where we are trying to educate people to say, "Well look if you feel that you are in that you are in that state, don't you think you should go back to your doctor and say, "Well I don't want to stop them because that's lethal", it can kill you to stop these medications, erm, "But can I reduce it a little bit and go down?".

Sammy also shared his experiences with the medication side-effects: *"But the psychiatrists don't realise this and it's all down to money if you want the truth, Depakote is a new drug and therefore more expensive, there's an older drug called Carbamazepine which acts just as good as Depakote, doesn't cost as much but the pharmaceuticals are pushing the doctors to prescribe Carbamazepine, bugger the fact that someone can lose all their teeth, you know, and that's wrong to me".* Sammy also stated that he has not seen psychiatrists on a regular basis, and when he did he often saw a different one each time: *"I have never seen the same psychiatrist each time I go in, well that's a waste of time because that person is only going to look at your records and doesn't really know or understand you".*

"Well my diagnosis was right, I can't deny that the diagnosis wasn't correct, I think some people do get misdiagnosed, erm, some people get told they've got something else when they've got bipolar, er, and vice versa, but in my case I think he was right, I think it is a case of he diagnosed me correctly um, whether he overprescribed the drugs at the time er I cannot confirm or deny that because I wasn't in any state to do so".

"Getting back to doing things which before was absolutely normal"

Through his work through the self-help group and helping others to also access community leisure activities it appears that Sammy has found a new meaningful role, which has been particularly helpful since the loss of his role within his work and consequent *"loss of prestige"*. Sammy described his family as being extremely supportive as well as the CPN's and Occupational Therapist, who helped him become more physically active and access sports in the community. During this time Sammy was also diagnosed with narcolepsy and told that he could not drive: *"You just feel like your whole world has ended again"*. Care workers supported him to use public transport and, *"Getting back to doing things which before was absolutely normal"*.

Sammy stated that through contact with the mental health research centre he was able to alleviate the shame he felt: *"Through talking and that I finally came to the conclusion that I should not be ashamed of my illness, I should accept I have what I have, and that I'm doing something about it, and I've done something about it to try and maintain as normal a living as possible, and that's what I've done, so yes to have the diagnosis has been a help in the long-term of being able to say, 'Yes, I now know what my problem is', I can now start to live my life accordingly and rearrange things to as normal as possible"*. Sammy further reflected: *"You do have to learn to live with it er, I've accepted I will have this illness, the double illnesses for the rest of my life, I've accepted that but I'm not giving up on life, I'm prepared to give up, I want to enjoy it as best I can"*.

Summary of Tina's narrative

Tina is a 49 year old female who was diagnosed with Bipolar Disorder (BD) 18 months ago.

Before diagnosis: *"I thought that was just a one-off"*
Tina shared that her parents died about a year before her diagnosis: *"I had a first episode and I recovered from that, I was back at work and thing seemed to be normal, and then I had another second manic episode that was a lot quicker and it was only after the second manic episode, I think it was probably about a year between the two episodes".*

"I was in erm I hospital at the time and I was going through a manic phase, so I'd had one manic episode um just after my mother's death and I'd got over that and I thought that was just a one-off and there was going to be no further problems, but then um I had problems at work again, um I was a teacher and the stress of working at school just got to me, so er I had um a manic episode and was in hospital and they said after that that because of the second manic episode and what they thought was probably depression in between that I was bipolar then so that was the first diagnosis, that was the diagnosis that I had then, because I was in hospital I found it quite difficult to um, and I was on quite a lot of medication, I found it quite difficult to come to terms with the diagnosis".

At time of diagnosis: *"This is a lifelong disability from here on in"*
Tina stated that initially she felt relief when she received her diagnosis. When Tina was asked what messages she received at the time of diagnosis she stated: *"Not a lot when I actually got the diagnosis because I was in hospital, they said, 'Right I think you're more bipolar, this is your medication'.* She stated that: *"My husband was at the meeting when they told me that I was bipolar so that helped, um, but I think it took me quite a long time to come to terms with it".*

Tina stated that she would have liked more information at the time of diagnosis: *"When I was given the diagnosis um, I was given the diagnosis literally a couple of days before I was discharged from hospital and I wasn't given any information with it, it was just, 'Right, you're bipolar, you're on Depakote, you're on Olanzapine, that's it, this is a lifelong disability from here on in, that's where you're at', and that's what I was told".* Tina stated that she and her husband have researched on the internet about the BD diagnosis.

Main reflections since diagnosis:

"I want to just have a normal life hopefully"
Tina talked about how she felt relief following the diagnosis: *"I suppose you feel relieved in some way that you've got a label and some explanation of what's going on, and I think after I'd had the diagnosis there was the relief that at least they know what it is and they can give me the correct medication, and I can now deal with it".* Tina went on to say: *"But there's also the problem that there are phases and you know if you're not careful, there will be another manic phase, there will be another depressive phase and so it's a double-edged sword really, it is a disability, and you know it is a life-long thing whereas before certainly on the first manic episode I thought it was just a one-off, it was exceptional circumstances, my parents had just both died within nine months of each other and I thought it's, my mental health is just a response to this and you know it's never going to happen again, but having had the diagnosis of bipolar it was the*

realisation that it could well happen again um, especially if I don't get the medication right, it'll be you know, the treatment right, it can be a cyclical thing almost, and that's what I don't want it to become, I don't want to become manic and then depressive, I want to just have a normal life hopefully.. it's difficult doing that".

Tina shared at various times within the interview her identity with BD: *"I still don't think of myself as bipolar in many ways, um, I have children and they say to me, "Is it genetic mum?", and I find that quite difficult"*, and, *"Sometimes but not often, and um, I know I'm not right but I don't think of myself.. well, I think I am beginning to think of myself as mentally ill but it's quite a hard one to feel that you know, you're one of those statistics".*

"I have found it hard not being able to work, um.. because that defines you for a lot of your life"

Tina shared her difficulties in building a support network since her diagnosis, especially since finishing at work: *"I've not worked since my diagnosis and that's been hard, and I think the not working has been hard, um because in not working I have more time at home and more time to reflect on things which sometimes isn't the best thing to do".*

"I don't think I would managed to go back to full-time teaching because of the stress of it and where I'm at mentally now um, but I've found that quite hard because it is a real disability".

"It's more growing old gracefully rather than a productive phase, and trying to be productive as well as ill is difficult".

"Well in that case you know we can't really help you anymore"

"I've been discharged from the psychiatric team because I wasn't ill enough but I feel that I now want to go back to the psychiatric team because I don't feel that I have a quality of life at the moment being depressed as I am, not working, not achieving in my daily life, I find quite hard… they'll say, 'Well you're not manic', and I'll say, 'Well no, but I feel low', 'Are you low enough for suicide?', 'No', 'Well in that case you know we can't really help you anymore", and I find that quite hard'".

Tina described the lack of support she felt from mental health services: *"I've been discharged from the psychiatric team because I wasn't ill enough but I feel that I now want to go back to the psychiatric team because I don't feel that I have a quality of life at the moment being depressed as I am, not working, not achieving in my daily life, I find quite hard".* This is in contrast to the self-help group which was: "*Almost a camaraderie… being in it with someone else makes it um more bearable".*

"I think it's been an easy excuse"

"I think it's been an easy excuse and especially with it being bipolar it's an excuse to say, 'Oh, I'm just feeling depressed today and not doing anything', and 'I'll just go back to bed now'".

"I think it's unhelpful in that way in that you can sometimes not take responsibility, but I think certainly in order to control it properly you do need to take responsibility and that's where it's hard, um, and sometimes I feel I'm always being a bit immature about it do you know what I mean, just er, hiding away from it".

"A label in order to put you in the right box"

"Diagnosis was very much a label in order to put you in the right box and I think because of being there that was the only way to do it, to have a diagnosis, to have a name to put on that box, if I think, if I hadn't of been in hospital and it'd been more in the community I think it would have been different and I think there are you know um other ways to explore things so that you're much more of an individual there and if for example it is just through um the talking therapies and it's you know this is what's happening, I think it might be this but it might be this, but you know I think it's not quite so cut and dry, but certainly because it was in hospital it was very much black and white, a little box I was being pigeonholed in".

"Felt the professionals have the answers"

I sometimes used to fight to get out of it but it's sometimes just quite comforting to be hiding in it as well, um, so.. I think I put my faith in you know the doctors and psychiatrists and said, 'Right well if you're giving me the right medication, fair enough', and you have that faith in them but occasionally you do sometimes think, 'Hmm well is that the right diagnosis, is it the right medication, it is the right treatment?', and then you do question the whole system".

"I think my upbringing and the fact that I've been part of a family who've always you know felt the professionals have the answers and you know you listen to professionals… I've never been involved in a situation where professionals have got it wrong… I think that's made me trust professionals and um respect professionals, so that's why I still feel that's you know the way it should be".

Summary of Tom's narrative

Tom is a 39 year old male who was diagnosed with Bipolar Disorder (BD) 21 years ago.

Before diagnosis: ***"It took me seven years to come to terms with losing my father"***
Tom described events and experiences that he had prior to his diagnosis: *"I remember um things people would do to embarrass me in front of the whole class and that just fed the paranoia and the depression so I was always reeling from that, I could never get on top, I could never get (inaudible) control… the death of my father when I was 11, bullying at school but I would also say my mother's upbringing cos I never had a room where I could put my own posters on the wall, decorate it how I want, choose my bedding, you know, choose what clothes to wear, um, so yea, um, embarrassment was, is is really bad for teenagers because it really damages their self-esteem, you know, and it was only when I went to university that I suddenly thought, "What, these people like me, I can make friends like that" (clicks fingers), you know, "It's so easy", and of course then the mania starts because you start bigging yourself up… basically everything got too much to me at university and being able to finally express myself and be the person I wanted to be all this time… and that's when I went over the top and erm and ended up in hospital from a manic episode that then set me crashing down into a depression".* Tom later in the interview went on to say: *"How many times in life can you take the knocks before it completely floors you".*

At time of diagnosis: ***"It was frightening"***
Tom stated that his diagnosis wasn't helpful to begin with because it was not explained: *"All I can remember is that the psychiatrist who gave me the diagnosis wasn't very helpful to put it politely, he basically told my mum you know well, 'Just thank god like we've, thank goodness we've diagnosed him now rather than later on in life, at least we can do something about it', kind of thing, but he didn't give me any, you know, therapies or whether it's psychological therapies, psychotherapists or psychologist or counsellor, there's no mention of any of those kind of talking therapies that would have helped me get my head around this diagnosis cos you're just kind of given a diagnosis and you think, 'Oh this is something you're going to have for the rest of your life', that you're going to have to deal with, and the psychiatrist all he does is prescribe pills, and then monitor the effects of those pills and if they're working or not by stablising your mood or pulling you out of a depression or anything else, um, so he really was to put it politely very unhelpful, er, and I was just left with a diagnosis with no explanation as to what it meant, what the implications were, what the consequences were going to be, erm, and so it was frightening".*

Main reflections since diagnosis:

"It's like chucking a live grenade in a room and then bombing it"
Tom reflected about how the diagnosis was presented to him and how this was not acceptable: *"You're a human being and you deserve respect and to be handled with care, um, and I don't think when someone just gives you a diagnosis of, "Well we've got a diagnosis, we know what it is, we can give him this medication, he can get on with it", it's not enough, it's not good enough, you know, it's unacceptable because you just dumped a load of shit on someone and then just said, "That's your shit, you get on with it, we're fucking off now", not acceptable".* Tom said more emphasis needs to be on how it can be managed and coped with: *"It comes*

at a moment of crisis and not enough information is given to the person that this isn't a death sentence, this doesn't mean that you're not going to have all the wonderful things in life like university, meeting partner, having a fantastic job, being able to hold down a fantastic job that you really enjoy doing rather just living to work, rather than working to live".

"It's not a death sentence"

Tom shared how he perceived his diagnosis now that he "accepted" it: *"A diagnosis helped me because I could blame something other than myself, I could say well, 'I've got bipolar', you know, it allows you, the positive thing about bipolar is you can blame something else, you can say, 'Well it isn't me, it's my illness', you know, so even though you would act funny and strange and have all this odd behaviour it's not you, it's not your personality, it's just an aspect of it that is you when you're ill, so it becomes easier once you accept that you have this diagnosis and then can find ways to move forward, lots of people don't accept the diagnosis and don't get treatment and won't take pills, you know, and won't speak to the counsellor and they're going backwards the whole time".*

"I almost stigmatised myself with the diagnosis"

Tom shared his experiences with those around him since his diagnosis and how he perceives and shares it with others: "*All my friends were very accommodating and very understanding and just accepted that I had this quirk if you will, um, so I've never really um felt discriminated against because of the diagnosis, I think you know in terms of feeling on the wrong side of something um it's to do with my personal, you know, self and that the guilt and regret for things that I may or may not have done that I'm imagining or that may have really happened or just figments of a manic or depressive state of mind that were just illusions you know, so the stigma, you know, I almost stigmatised myself with the diagnosis and thought, 'Oh', you know, 'I'm', and then as I've seen from so many other people they talk about being a bipolar sufferer and almost as if they're a victim of this condition and they let the condition control them but what I learnt early on with my bipolar is that I didn't proclaim it, you now, I didn't announce it to everybody, but I didn't hide it either and if it came up in conversation it came up in conversation and most people um were quite accommodating, you know, and they just took it like as if I had diabetes or a broken leg or something like that".*

"You're not meeting those milestones at the same time"

Tom talked about how experiencing an "episode" can impact on how a person experiences expected milestones: *"If you have an episode it sets you back, it takes you six to 12 months to recover from that to get back to where you thought you were but the trouble is 12 months have passed since then and everybody else has moved on so when a normal person is reaching all the milestones in life, you know, going to high school, going to college, going to university, meet their partner, get married, having kids, you know, having a job and all the rest of it, you're not meeting those milestones at the same time".*

"It resets the chemistry in your brain"

Tom talked about the drugs he has been prescribed and described mixed experiences about how these have helped him: *You take a drug it's for a chemical imbalance in your brain and I now take an antipsychotic cos I was on lithium for years um… but it didn't stop me having the highs and the lows, and it didn't really level me out"* and, *"I think to get to the underlying problem requires medicine and psychiatry, you know, if I didn't take an antipsychotic I do not know where I would be or if I would have been able to manage myself so well".*

"It's kind of nice but I feel like I'm stuck in neutral"

Tom explained that attending self-help groups have been helpful: *"That was a real help for me to move forwards and I went for a couple of years not having an episode and then I had my last episode in 2008, six months after I'd split up from my partner, my son's mother"*. He talked about how he has changed his life to enable himself to move forwards: *"I've engineered it that I've got a life just so where I don't have to work, you know, because of my illness, because of how severely it's affected me and I've been hospitalised on three of four occasions and had about five or six different episodes, um, you know, and my life is just so, it's kind of nice but I feel like I'm stuck in neutral and I'm stalling and I suppose when I had the diagnosis to begin with I was frightened that I would never progress and realise any potential that people thought or I thought I may have had, you know, and you think, 'He's going to stagnate here, you're going to go backwards, you're not going to go forwards from this', and it is very very frightening especially when nobody explains it to you, and everyone's fumbling around in the dark for answers"*.

Appendix D

Compendium of participant's direct speech and thoughts

Messages from professionals

If you don't open the door, I'm calling the police
We're breaking in and I'll have you sectioned
You need medication, you need hospitalisation
Oh do you not know
You have a mental illness
I think you've got bipolar
Well it might be this but I don't know
Nah there's nothing wrong with you
There's never been any evidence of this
I'm so sorry, I seriously got that wrong
Yea, there's something seriously wrong
There is something wrong with you, you can do something about it
You don't look like someone who has bipolar
We know what those people look like
I've seen worse
Well you've got these but you haven't got these
Have you ever?
Yea, there's something in your notes
Oh, you've been in hospital, I think we'll take that as a given
We feel that you've got bipolar from what I've been told
We can treat it
We can't do that unless you've got a diagnosis
Right I think you're more bipolar, this is your medication
A shift in diagnosis was appropriate
Oh, he can just look it up on the internet

It's chronic
It's not cureable
This is a life-long disability from here on in
This is something you're going to have for the rest of your life
You're very unwell, you won't work again
There's so many more possibilities now that we can offer you as treatment
These are your options, these are the drugs you can take
Take your pills, stop drinking and you'll be fine
How can I help you today
No we can't help you, you've got a drink problem
No we can't help you, you've got a mental health problem
You've got a diagnosis, take your pills you'll be alright
We'll increase your anti-depressants
Oh she'll be alright
You're doing better than the others
This is as good as it gets
Everybody has ups and downs
I'm going to use you as a guinea pig
I'm afraid you might go high
We've lots of others on Quetiapine and they're having a really tough time
If it's not broke, don't fix it, stay with it
I really don't need this today

You're not ill enough
I think you're well enough
You've got bipolar, get on with it
Are you low enough for suicide?
In that case you know we can't really help you anymore
Keep on taking these pills and get on with it
That's your shit, you get on with it, we're fucking off now
This is where you're at, sort it out yourself
Oh we'll see him next week
That's good, you've working with normal people
You're being discharged because you've got a job
Look psychotherapy exists
I don't believe in bipolar

My own voice

There is something really really wrong with me
What's the point in being here, I'll string myself up cos I've had enough
I really don't need this in my life, it's not very nice
I really need an appointment with somebody who can help me
Oh no, not another day
I don't want to be here
I'm feeling really shitty this is how low I am
Everybody's going to be miserable without me
You were taking too much, they don't like you, what an idiot you were
I don't know why I'm so upset
Buck the fuck up
What's wrong with me
I really need to speak to someone
My god, that's me
Yea I do have bipolar disorder
Nah, I'm pretty sure I don't
I wouldn't have recognised that about myself
No I bloody haven't, I haven't been that bad
Yes, it explains a great deal
My life is ready to start
They can fix it now we know
Why can't the doctors do this for me?
I didn't ask to be bipolar
Oh what a pile of shite
I thought this was gonna be the beginning of getting better
Well is that the right diagnosis?
Is it the right medication?
Is it the right treatment?
I don't understand this
I haven't got the energy anymore
What should I do?
Am I going psycho?
I'm not loony

I've got to manage this
I can't do this to this little boy, I have to get well, I have to be right for him
I'm going to buy into this bipolar stuff in order to feel better
Bloody hell this doesn't go away
I actually am disabled by this, it is something that's stopping me doing things
How fucking weak am I?
If I could do that then why I can't I do it now?
Why do I feel like this because I know I can do that?
Oh my god, so I'm not bipolar, I'm just a terrible person
I must just be lazy
I'll just stay in bed quietly and nobody will bother me
I'll not bother anybody else
Well it isn't me, it's my illness
This is part of the illness
Oh Jesus, am I bipolar or do I pretend I'm not?
I don't mind wearing a label bipolar
We'll go to the coffee shop and you meet us there
She said, "Let me take you", wow, what a lovely thing to do
I have learnt more from those people than I ever learnt from the medical people
Somebody believes me
Somebody is taking me seriously
Recognise the pain I'm suffering
This medication does work
Why am I taking this medication, do I really need it?
Well it's doing more good than harm so I'll just carry on
I think I should come off this cos it's not doing me any good
It's too much, it must be wrong
Surely it wants cutting back now
Why can't I do certain things, why can't I hold a job down
Is this acceptable or is this over the top?
Sod it
You don't know what's inside me
I'm proud of what I've achieved
Please don't judge me harshly
I'm bipolar, this is me, this is who I am, no more need to be said

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Messages from others

You're horrible, you're fat, you're ugly, no one will ever love you
Stop being stupid
What the hell's up with him?
What's he got to be miserable about?
You know there is something not quite right
I don't know what it is
Poppy's just being stupid
She's causing a fuss and a scene
There's nothing really wrong with her
How dare you say she's got a mental illness
I don't know why you want this label
Don't talk rubbish, you're just badly behaved

Ha ha you're a sex maniac, (Not *maniac*, I said manic)
Oh do you know what Mary's done, do you know what Mary's done?
Why's he doing that?
He's not in his right mind
You're not like you used to be
That's your illness
What the bloody hell is that?
You don't seem like that mum
Is it genetic mum?
Are you alright mum, just watch out

Why don't you just pull yourself together
Don't be stupid, get out of bed, pull your socks up
Hang on a second, you're becoming obsessive again
Look at how she hogs every conversation
Oh you blow hot and cold
Slow down
Calm down
We'll just keep calm
What've you done?
You mustn't do this or that because it might upset you
Have you got your pills with you?
Have you taken your medication?
Have you taken your pills?
Have you taken them?
See I told you there's nothing wrong with you
If I ask you again tomorrow you'll have changed your mind
When you're ill who's the one person that looks after you puts you back together again, it's me
I am absolutely sick and fed up and tired of this damn bipolar
It's not a disease it's how Ben feels
Ahh, sorry Ben, that's really sad
I know what you're going through
I don't get it
Time to stop relying on this whole mental health gig and move on

Running Head: REFLECTIONS OF PSYCHIATRIC DIAGNOSIS

Section Three: Critical Appraisal

Reflections upon my own stance of psychiatric diagnosis

Roisin Turner

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

My research paper explored service users' experiences of receiving a diagnosis of bipolar disorder (BD). There was a focus on the messages they received regarding their diagnosis and consideration of how their own voice was encouraged and heard within this process. The main strengths of the paper were enabling service users to share their narratives of the difficult journey they have experienced, and using a narrative approach that allowed them to direct their interview. The main limitations mainly related to the sample. Twelve participants, although providing a depth of interview material, may have been optimistic to use for a narrative approach. Using a smaller sample would have allowed analysis in more detail. The sample also consisted of service users who were intelligent and driven individuals, and the majority were involved either in a university research group or service user support group. This may not be a representative sample of people who have received a diagnosis of BD.

Within this critical paper I will be reflecting upon my own stance of psychiatric diagnosis and how this has changed and been challenged over the course of the study. This will include consideration of the ethical points that arose in terms of diagnosis and consent, and the issue of power that practitioners have within research and clinical practice. I will also reflect upon the narrative method and how this has influenced my perception of my future clinical approaches; this includes a consideration of the use of non-spoken narratives.

Reflections upon my own stance of psychiatric diagnosis

My own personal interest in this research originated from working with people who have been given psychiatric diagnoses. My work within different placements during clinical training highlighted the different approaches that services adopt. My child and family placement used a medical model approach, and children were placed within specific pathways directing specific interventions based on their presenting difficulties. Reflecting back now I feel that it was stifling for both the client and myself as it was difficult to provide an individualised intervention based on their specific needs. Within my adult and specialised third year placement, both of which were working with adults in a community setting, I was able to create psychological formulations with clients. This enabled the client and I to collaboratively decide upon the difficulties they would like guidance and support with, and what form this would take, for example, individual intervention based on an approach that suits them, group work, and access to community led support. I found this approach much more empowering for the clients and it encouraged me to think about how best their individual needs could be met. I also noted that during my work with clients that neither they or I discussed or even mentioned their psychiatric diagnosis. Upon reflection I think this is because I felt completing a formulation with them gave me much more rich information about their difficulties and possibly where these may have stemmed from. It was not something that clients brought up either and I was not sure why this was; perhaps they felt able to share their narrative with me and therefore their diagnosis became less significant. My role as a professional may also have influenced this; being in a position of power and influence my non-attendance to the diagnosis may have discouraged them from mentioning it.

Through teaching we have received at university and from hearing other professionals talk about service users and their diagnoses, I became aware that my feelings about psychiatric diagnosis were quite strong. I perceived diagnosis for mental health difficulties to be very reductionist and felt it ignored the voice of the individual. I had become more aware of books and articles being written about the negative aspects of diagnosis, for example, Richard Bentall (2003), Mary Boyle (1991), the Division of Clinical Psychology (DCP, 2013) and David Pilgrim (2007). Everything that was being said made sense to me and urged me to continue to think this way. I was however aware that others did not think the same, and for me attending to the voice of the people who have been given a label was of great importance. I wanted however to ensure that I was not placing greater emphasis on my own needs and values. Therefore I decided to focus my research paper on listening to service users' voices so that I could then re-consider my own stance regarding diagnosis. I decided to look at this as the main theme within my Critical Paper because I felt that this self-reflection would help me consider my emotional connection and thoughts with this, and with this reflection positively influence my future clinical practice (Imel, 1992).

Research has found that self-reflection also increases professional satisfaction and is more likely to reduce 'burn-out' (Hurley, 1997; Schon, 1983). Throughout the research process I kept a diary noting my thoughts and emotional responses to situations and interviews. Self-reflection can be achieved successfully through different mediums including writing (Pennebaker, 1997) and personal therapy (Timms, 2010; Wigg, Cushway, &

Neal, 2011), which I have also used throughout my clinical training. Personal therapy has allowed me to consider more deeply the emotional aspects of my work with clients, rather than purely exploring these on an intellectual level in supervision. I feel that this reflective process is particularly important as I am coming to the end of training. Once qualified I am likely to hold roles in which I am supervising staff from other disciplines who may have different views to myself, and I am likely to be required to attend multi-disciplinary meetings where my opinion of a diagnosis may be invited. Considering my opinion now will aid me in these situations but also to draw on elements that I have been privileged to hear within the research. I am also aware, as with psychological formulations, my opinion will not remain static and will need to change over time as I am exposed to more knowledge and range of opinions throughout my career.

In a recent teaching session regarding psychiatric diagnosis we were asked to stand in a line to represent how strongly we felt regarding diagnosis. It was only doing this exercise that I realised how my views were stronger than others in my cohort, and I reflected that they had actually deepened following completing the research paper interviews. I have considered the reasons for this, and reflected upon personal aspects such as a child I may have felt that my voice was not heard so I feel strongly now that others should have opportunity to share their story. Relating to this I have considered the new Diagnostic and Statistical Manual of mental disorders (DSM-V) (APA, 2013), which has now included the term ‘shyness’ within the Social Anxiety Disorder category. As a child and teenager I experienced shyness and even to a degree now, mainly due to a lack of confidence in myself. This however over time has diminished and is more likely to be noticed when I am in large groups of people. I find it alarming that my behaviour as a child may have been 'diagnosed' if I was a child now and that I potentially could have been given medication for this. I feel that personality traits such as this and mental health difficulties are best thought of as on a continuum and I consider them as variations of normal human behaviour. I believe that my shyness and mental health difficulties can be explained, and often they are responses to attachment or relationship difficulties, distress or trauma to varying degrees.

I have considered other aspects such as my personal values, and how these have influenced my opinion regarding diagnosis. I do have concerns that when I am qualified I may stand out from others because I may be deemed as possessing an extreme viewpoint regarding diagnosis. When we did the exercise in teaching to visually show where our views were in strength, I felt a degree of pride to stand at one extreme and show this as my personal view. However I am aware away from the security of my cohort this may change once I am qualified and I may feel pressure to conform to the dominant group in order to fit in and reduce possible rejection (Sue & Sue, 2003). My opinions are though closely tied to my values, and these are a part of my self-identity. I value aspects such as community, compassion, growth, making a difference and understanding. These have been strengthened during clinical training by associating with others who also have similar values, and these values being fostered by the university as well. Diagnosis does not fit with my values as it can often take create an individualised approach to emotional difficulties, and ignores the wider aspects such as the influence from societal pressures and culture (Harper & Speed, 2012; Rapley, Moncrieff & Dillon, 2011). I feel that current society has moved away from the close-knit communities we had in the past meaning a possible shift of community and societal values to more self-based values. Community networks and self-help groups are starting to work towards a more accepting and community led support for those with mental health difficulties, for example, the Soteria Network and Open Dialogue. My interest in this has grown as I have increased my knowledge about these approaches, and I am planning on visiting sites in England that have started to use the Open Dialogue approach.

I have considered why categorisation is often used and I recall an exercise that I did at college in an A-Level psychology session. The class was asked to think of themselves and other people such as friends and family, and rate how they generally behave. We were asked to share our responses; everyone in my class placed others into categories of how they generally behave but for themselves they placed themselves in the 'depends on the situation' category. I however was the only one who placed others and myself into the category 'depends on the situation' because I knew from my experiences that how I behaved in one situation might be different in another, and so I made an assumption that others would be similar. Since then I have reflected that people do tend to place others into categories; perhaps this makes them appear more 'predictable' and reduce ambiguity or uncertainty. Social identity theory (Tayfel & Turner, 1979) may also play a role in that we categorise people to understand our social environment. Categorisation allows us to identify with others, which helps build our self-esteem. We may also compare our group with other groups, which can lead to competition and prejudices. Categorising people can make our lives easier particularly when we are faced with complex issues (Macrae, Bodenhausen, Milne, & Jetten, 1994), such as understanding human experiences and emotions. However having categories can lead to expectations that a person or group will behave in a certain way and thus may influence self-fulfilling prophecies (Snyder, Tanke, & Berscheid, 1977; Word, Zanna, & Cooper, 1974). For example, as with the research participants they stated that certain behaviours they deemed as 'normal' were perceived by professionals to be evidence of their diagnosis.

Psychiatric models often assume that symptoms or behavioural difficulties are primary problems which can be directly 'treated'. Lemma (2006) suggested that a symptom is a secondary consequence rather than the cause. For example, she suggested that a client may present symptoms associated with eating difficulties, yet the underlying conflict may be related to intimacy and a fear of their emotions. This for me is why using psychological formulation is far more useful in understanding the causes of a person's difficulties. Making meaningful connections between events and experiences can create a comprehensible narrative which allows personal ownership by the client (Corrie & Lane, 2010). The DCP (2011) recommends that clinical psychologists formulate from a broad-based, integrated and multi-model perspective which locates personal meaning within its wider systemic, organisational and societal contexts" (p. 2). I attended the 2014 DCP conference and heard clinical psychologists and other professionals talk about how avoiding focusing on the social context serves the powerful and not the powerless (Mary Boyle) and we need to start listening to people's problems instead of diagnosing them (Lucy Johnstone). Mary Boyle also stated that clinical psychologists need to build an alliance with community psychology, and I was inspired by all these words.

The participants within the research study shared their opinions regarding how they would see alternative systems, but for many they felt that alternatives were not achievable. They stated that they would like more support within the community but conceded this was dependent on money provided for services, which was determined by the political party in power: "It's just all about the politics so much of the time" (Claire). This has been very timely with regards to the May 2015 general election and campaigns to fight for the National Health Service and increase spending within mental health. There is a need within current society for 'quick fixes', and diagnosis may be driven by society's needs. There is debate that the monetary and power desires of pharmaceutical companies and academic psychiatrists play a role in the push for diagnosis and drug treatment (Whitaker, 2010). I think that there are alternatives available and we should not 'accept' a badly setup system which increases people's stigma and distress rather than encourage understanding and acceptance.

Privileged position and power

I felt a personal privilege to be part of the participant's storytelling experience and allowing me to hear their words. I noted my emotional connection to their words when I was listening back to the interviews, remembering how I felt at the time of the interview. I reflected that some participants moved me more than others, for example, with Alice I remembered a lot of laughter in her interview, but I was deeply touched and felt overwhelming sadness when she talked about how her mental health difficulties had impacted on her relationship with her sons. Listening back to the interviews I was moved emotionally more than I expected to. Hearing the stories and feeling connected with that person, I really felt that some participants had opened up to me emotionally when relaying their personal stories. I experienced a sense of personal responsibility towards the participants in ensuring that their voices are heard through the research. I was aware of the danger of privileging those accounts that resonated with me, and it may be that I was encouraging or discouraging, through my line of questioning and non-verbal communications, particular voices.

Some of the participants' emotions were heightened during the interviews, perhaps making me less exploratory around areas I sensed were emotionally vulnerable for them. I recall being more vigilant to cues about their level of comfort and readiness to talk. As Smith, Flowers and Larkin (2009) advise, researchers have "ethical responsibilities towards the participant" (p. 66), and on occasions it seemed inappropriate to pursue a certain line of questioning. When one participant became upset I encouraged her to talk about what she felt comfortable sharing, and used silences as a way of allowing her to think and decide how she wanted to proceed.

I was also aware of the different role I had as a researcher compared to a clinician. When hearing the narratives of the participant's early experiences I felt an urge to want to discuss this with them to help aid their understanding about how their past experiences may link to their current difficulties. I felt as though I was asking them to open up and I was not able to not give them something back other than my gratitude for their openness. I am aware of how both roles, researcher and clinician, hold a degree of power and authority, even though I do not intent this. During the interviews I heard stories of experiences such as diagnoses being made and never being shared with a service user, occasions when people are over-medicated, and decisions being made when a service user may not be in stable enough to make those decisions. For example, Alice, talked about the use of electroconvulsive therapy (ECT) when she was in hospital. With hindsight she would not have agreed to this, saying that she signed the consent form because staff recommended it. Poppy also shared her reaction when a clinical psychologist told her he "did not believe in bipolar". Poppy stated that on an intellectual level she agreed with him but as a service user with no other alternative offered by him, this was her only hope: "It could be my only thing I'm holding onto, it's a diagnosis therefore the medication can work, I'm clinging to this, 'I don't believe in bipolar', oh no I've got to drown then". This really resonated with me, and one of the lessons that I will take from this study is that my attitude about certain treatments or the use of diagnosis might not be shared by those with direct experience of it. Some may find the long-term use of psychiatric medications or ECT to be life-saving; others may explain their experiences within spiritual or religious terms. Neither of these are opinions I personally hold, but as a phenomenologist, I cannot assert that some frameworks of meaning are 'accurate' or 'valid' and others are not. Respecting the diversity of others' accounts and experiences often necessitates making room for viewpoints that are disconcerting to our own beliefs and emotions.

Narrative approaches

I was made aware of the personal gains some of the participants may have found from participating in the interviews. One participant expressed excitement in taking part in the interview, which at first surprised me. However I realised that this was providing them with time and space to reflect upon their experiences and the majority of the participants appeared to be actively reflecting about their experiences and the impact diagnosis had on them, as though they had had limited opportunity to do this previously. I started to appreciate the powerfulness of the narrative approach, and how it gave them an opportunity to share their experiences.

One of the participants, Adele, used diaries as a way of communicating and remembering her experiences, particularly when she was in hospital. She talked about music and its relevance to her when she was struggling emotionally. Whilst reading through the transcipts and putting together the narrative summaries I listened to classical music as this aids my concentration and I find it inspiring. Music is thought of as being narrative (Imberty, 2008); it has the power to involve listeners and evoke emotional responses. I found myself constantly drawn to and listening to the 'A beautiful mind' film soundtrack. The film is a story of John Nash, a man who was diagnosed with paranoid-schizophrenia and whose mathematical genius earned him a Nobel Prize. Sadly he died very recently which makes this even more poignant for me. On the soundtrack the composer, James Horner, chose to write the score according to the character and narrative. He captures a range of emotions from happiness and love to sadness and fear, and I felt a strong connection to the music and also the association with the film. It depicts the internal struggle that John Nash experienced: his ambition and intellect, his struggle to find love, to find peace of mind, to deal with his mental health difficulties and to get back to a path of health. His journey incorporated different themes such as experiencing very distressing times and creative times, which participants in the research study also described.

I felt that the music represented some of the participant's stories, in particular Poppy. I felt her narrative gave an emotional insight into her experiences, particularly the difficult experiences as a child and young adult when dismissed by those around her. Listening to the music and reading the transcripts also provided me with feelings of frustration as depicted in the film when John Nash was taken to a psychiatric hospital and his thoughts and emotions dismissed by the staff, as too were some of the participants. This was a significant thread through their stories, that they were not listened to, dismissed and felt rejected by those they wanted support from. I also felt a sense of hope that there is an alternative we can offer to those who have struggled in their lives. We can offer people an understanding without providing labels that may take away their positive identity and hope.

One song, "A kaleidoscope of mathematics", was according to James Horner, a representation of the chaos of John Nash's inner life. His experiences and emotions being shown through the imagery associated with a kaleidoscope such as unpredictability, colour, patterning, and energy

(Lehman, 2013). This representation may also parallel with the participants lives, however where they see parts of their life falling into chaotic forms, I can visualise patterns, for example through the use of psychological formulation. Being aware of their past experiences helped me understand some of their current difficulties. The film has one main inaccuracy in that John Nash was medication free which was not depicted in the film. During an interview he stated that, "The doctors and those who treat people with mental illness, they want to stay in business". This was a similar viewpoint to one of the participants, Ben, and this saddens me that this alternative medication-free experience, which could be inspiring and create hope for others is not shared.

Future practice and research

Through this research process I have gained insight into the world of others who have shared their personal and emotional experiences with me. I have at times felt overwhelmed by the amount of interview data and felt I have not given justice to the participants' experiences and words. My disappointment however only encourages me to ensure that these words are shared, and so I endeavor to publish the research paper. I also feel that I have enough interview data to write further papers which could explore specific areas, for example, looking at the participant's self-identity and how this has changed over time.

In terms of future practice I have reflected that my views regarding diagnosis and the medical model might not be shared by others, and this may feel at times challenging and frustrating. It will be important that I can discuss my feelings within clinical supervision and perhaps confide in colleagues who share similar opinions to myself. I have learnt that discussing a client’s diagnosis with them will enable me to hear their personal story and I can provide them with the space to develop their own narrative, which can hopefully empower them and provide them with hope.

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Section Four: Ethics Section

Living with a diagnosis of bipolar disorder: A narrative analysis

Roisin Turner

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Ethics Protocol

Living with a diagnosis of bipolar disorder: A narrative analysis

Name of applicant/supervisors/affiliations/version number

Applicant: Roisin Turner (Trainee Clinical Psychologist)

Supervisors: Dr [redacted]

Professor [redacted]

Version: 2

Living with a diagnosis of bipolar disorder: A narrative analysis

Psychiatric diagnosis has received many criticisms over the past century (Pilgrim, 2007), and the most recent Diagnostic and Statistical Manual of mental disorders (DSM-IV) has stimulated public debate about it's reliability and necessity. One main criticism is reducing psychological responses to experiences into a label which takes removes the individual's personal meaning (Johnstone, 2006). This study aims to explore the stories and personal meaning for those who have been diagnosed with a psychiatric disorder, specifically bipolar disorder. Until recently the diagnosis of bipolar disorder has been neglected within research (Jones & Bentall, 2006), even though the diagnosis of bipolar has receieved great criticism.

The American Psychiatric Association (APA, 2013) describes bipolar disorder, previously termed manic depression, as a psychiatric diagnosis given to those experiencing alternating episodes of mania and depression. Manic symptoms are described as racing thoughts, delusions of self-grandeur, partaking in risky behaviors and reduced need for sleep. During depressive periods, patients commonly report experiencing reduced mood, changes in appetite, and irritability (APA, 2013). It is reported that those diagnosed with bipolar disorder have a suicide rate approximately 20–30 times that of the general population (Pompili et al, 2012).

An online survey of people who have been diagnosed with bipolar disorder and their families (carried out by Bipolar UK, Bipolar Scotland and the Royal College of Psychiatrists, 2012) showed that many people were not diagnosed for more than 13 years after they had first started experiencing symptoms. Eighty-five percent 85% of more than 700 people surveyed were diagnosed with a different diagnosis, most initially being diagnosed with depression, before they received a diagnosis of bipolar.

There are strong movements from clinical psychology in particular for a move away from psychiatric diagnosis and to view mental health difficulties as multidimensional and on a continuum of human experience (Division of Clinical Psychology, DCP, 2013; Gill, Mullin & Simpson, 2013). Charities have also become more vocal regarding the use of diagnoses and the potential impact upon individuals. The chief executive of mental health charity Mind, Paul Farmer, has stated that although a diagnosis can give people access to treatment, support and services, there are the negative aspects such as receiving the wrong diagnosis, stigma and having a label (Mind website, 13 May 2013).

The DCP (2013) highlighted the importance of service user views with this debate. They highlighted that often service users find that diagnosis can have some benefits, for example, offering assurance that they are not to blame for their difficulties. This was found with adults reflecting back on their childhood diagnoses of Attention Deficit Hyperactivity Disorder (ADHD), Generalised Anxiety Disorder (GAD) and bipolar disorder

(Bringewatt, 2013). Dinos et al (2004) found that service users who had received various psychiatric diagnosis across the sample, including bipolar disorder, disclosed negative experiences such as stigma and discrimination. However some also expressed relief in receiving a diagnosis, and some thought that through acceptance of their diagnosis they as a consequence were better adjusted.

The aims of this research are to explore people's narratives regarding their journey to and following receiving a diagnosis of bipolar disorder. This will enable professionals to gain a greater insight into how useful and unhelpful psychiatric diagnosis is for service users, and add service users voices to the debate of the current system of diagnosis.

Method

Participants

The target sample for the research is up to 12 male and female adults aged over 18 years who have received a psychiatric diagnosis of bipolar disorder by a psychiatrist. There is no exclusion criteria regarding the length of time since diagnosis. This sample size is appropriate for the purposes of this research design which is to gather views about experiencing and living with a diagnosis of bipolar disorder through in-depth interviews.

Initially all those who are currently on the [redacted] database and who receive the [redacted] newsletter will be asked to participate via letter sent from the [redacted] team. If there are a lack of volunteers, then a further recruitment phase will be employed via north-west support group attendees. This would include [redacted], which has over 12 support groups within the north west.

Design

This is a qualitative study which will use interviews to identify key issues and themes from service user's experience of a psychiatric diagnosis of bipolar disorder. Narrative analysis is compatibility with a constructionist paradigm (Crossley, 2000), which is aligned with the author's theoretical position, whereby meaning is co-created by interviewer and participant. By listening the participants' narratives the interaction between participants and their diagnosis can be explored. In particular how participants construct meaning about their diagnosis and how they make sense of their diagnosis over time.

Procedure

Recruitment will be phased so that initially only those who are on the database and who receive the [redacted] newsletter will be invited to take part. This process will prevent an excess number of potential participants being asked. The [redacted] will inform potential participants via the July 2014 newsletter edition that a study will be taking place soon. They are asked to contact the [redacted] if they are interested, and once ethical approval has been gained, these potential participants will be contacted by the researcher. Once ethical approval has been gained, information regarding the study will be sent out via the September 2014 edition of the newsletter. Participants who are able to attend a face-to-face interview will be prioritised. For those participants who provide a telephone number, the researcher will contact them to explain the study, and send a letter (Appendix B) and Information Sheet (Appendix C) to them. Those who provide an email or postal address will also be sent this information, and they will be asked to contact the researcher if they wish to take part. The researcher will offer time to explain the study further face-to-face or via telephone if they wish.

A second phase of recruitment will be used should there be a lack of volunteers by mid October 2014. This will involve sending the letters out to people listed on the [redacted] database. Although these people may also receive the newsletter, it cannot be guaranted that they have read the newsletter as this is sent to members via email. They will be asked to contact the researcher before the start of November 2014 should they wish to participate.

If there is still a lack of volunteers by the start of November 2014, then a third phase will be employed to recruit via north-west support group attendees. This would include [redacted], which has over 12 support groups within the north west. This will involve sending information to the organisers to pass onto the attendees with the researcher's contact details (Appendix A).

Once participants have verbally agreed to take part, they will be asked to complete a consent form (Appendix D). An interview date and time will be agreed. Demographic information will be gathered at the time of interview via a demographic form (Appendix E). A proposed initial interview schedule (Appendix F) has been drafted with key questions. This is purely a guide of questions that may be asked by the researcher, as the interview will largely be driven by the interviewee telling their story. There are key features that will be explored within a participant's narrative such as life chapters, key events and future scripts.

A semi-structured 60-90 minute individual interview will take place with each participant. The participant will be offered a telephone call from the researcher the day after the interview to ask if they have any questions or comments following the interview. All interviews will be digital audio-recorded and transcribed in full. The audio recordings will be destroyed and/or deleted as soon as possible after the thesis has been examined.

The typed transcripts will be encrypted, password protected and stored securely by the researcher and once submitted the paper documents will be scanned, encrypted and saved. The data will then be transferred and saved securely by the Research Coordinator in a password-protected space on the university server. This will be kept securely for a total of ten years by Lancaster University, and then deleted/destroyed.

Proposed analysis

The interviews will be analysed using Narrative Analysis (McAdams, 1993) as this allows individuals to tell their stories and themes to be developed from this. The research will follow an inductive analysis, meaning that the data will help develop a theory rather than looking for data to prove or disprove a theory, which will reduce bias in the coding of the data. Analysis in narrative studies does not simply look at the content to which language refers, it asks why was the story told *that* way? (Riessman 1993). Narrative analysis links well into theories of self and identity, and exploring lived human experiences (Crossley, 2000).

The interview data will be listened to and transcribed by the researcher. The data will be analysed by the researcher with input from the supervisors to discuss the themes identified. Analysis will involve the transcriptions being read repeatedly in order to identify recurrent and salient themes. These themes will be refined as this process continues in order to ensure that they are consistent with the interview data. Other elements will also be identified whilst deriving themes: narrative tone and imagery.

Practical issues

Potential costs for the research are travel expenses for service users, printing and photocopying, stamps and stationary for letters, telephone calls and room bookings for the interviews. Lancaster University will refund public travel costs or up to £20 petrol costs per service user. The university will also cover costs for printing, photocopying, stationary and postage, and use of a mobile telephone phone is available. Rooms at the university are available for free, or the researcher can interview the participants at their home if they prefer.

If the participant wishes to be interviewed at home, the [redacted] [redacted] Foundation Trust Lone worker Policy (June 2013) will be adhered to. This involves ensuring that a colleague is aware of when and where interviews are taking place, carrying an ID badge (please note: not wearing an NHS ID badge), arranging interviews during daylight hours, and having emergency contact numbers saved onto the mobile phone. The colleage will be informed of when the interviews will take place, and the address of the interview will be written in a sealed envelope. This will only be opened in the event that the researcher does not make contact at an agreed time when the interview has finished. If contact is made then the researcher will retrieve and destroy the address. There will be an agreement that if the researcher does not make contact by a set time they will try to ring the researcher and then ring the police if they cannot get through.

Ethical concerns

The main ethical issues are the use of adult participants who will be talking about parts of their life that may be upsetting to discuss. In an attempt to prepare potential participants full information regarding the study will be provided verbally and in written form for the participants. This will include information regarding withdrawal of consent and who to contact should they not be satisfied with any aspect of the process.

It is acknowledged that participants may experience some unanticipated emotional discomfort distress during or after the interview. Prior to the interview the participants will be asked about their current mood, and whether they feel they think participating in the research may impact upon their mental health. They will also be asked to provide their General Practitioner (GP) or Care Co-ordinator contact telephone number. They will be contacted prior to interview to check whether there are any potential risk issues. The limits of confidentiality will be explained to participants in that these professionals will only be contacted during or after interview if the researcher thinks that there is a serious and /or immediate risk of harm either to themselves or another person. If the researcher has concerns of any matter, they will initially contact their supervisor.

The participant will be offered a telephone call from the researcher the day after the interview to ask if they have any questions or comments following the interview. Participants will also be provided with a debriefing sheet (Appendix G) which will list contact telephone numbers for support services should they require support following the interview.

When arranging interview dates and times, it will be ensured that a colleague will be aware of the day and time, and have access to the knowledge of the interview location . The researcher will make sure that they or an appropriate member of the clinical psychology staff are available if advice is required or concern is raised about a participant during the interview. Ideally the interviews will take place at the university so that assistance can be sought quickly, and participants will be provided with information if they feel they need to speak to a qualified member of staff following the interview.

The researcher will explain confidentiality and anonymity as highlighted on the consent form (Appendix D) to each participant prior to interview. In terms of confidentiality, the participants information will be anonymised from start with use of a code number, and the participants will be asked to provide another name that can be uses as an identifier within the report. Confidentiality will only be breached in exceptional circumstances i.e. if it is felt that the service user is at risk of harm to themselves or others, and this information with be shared with my supervisors. The participants have a right to withdraw at any point until their data has started to be analysed and they will be provided with their own code number so as to keep confidentiality if they wish to withdraw. A codebook matching real names with pseudonyms and codes will be kept in a encrypted file which is password protected, in line with Data Protection requirements. Only the researcher will have record of participant's real names for the purpose of providing a summary of the research unless they wish otherwise.

Timescale

The following is an outline of the proposed research timescale:

August – November 2014 - Recruitment

September - December 2014 – Data collection

December 2014 – March 2015 – Data analysis and write up

March 2015 – April 2015 – Submit final drafts to supervisors

May 2015 – Submit final version to Lancaster University exam board

Following submission, a separate report will be disseminated to participants unless they have specified that they do not wish to receive information regarding the study. A copy of the research will be disseminated to the researchers at the [redacted]. As a condition from the university, the findings will be presented at a presentation day at the university in 2015. The authors will also look for opportunities to disseminate at national conferences, and will submit the paper for publication in a journal relevant to clinical psychology.

Conclusions

The increasing debate regarding mental health and relevance of psychiatric diagnosis highlights the need and importance of up to date research for this population. Using service users' experiences and accounts of what they found helpful and unhelpful adds a vital dimension to this debate. This study will start the process of filling the research gap in this area and inform mental health professionals regarding clients' views.

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Appendices

Appendix A: Poster advertising research

Appendix B: Letter to potential participants from the [redacted]

Appendix C: Participant Information Form

Appendix D: Consent Form

Appendix E: Demographic Information Form

Appendix F: Interview Schedule

Appendix G: Debriefing Sheet

Appendix A

Poster advertising research

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Do you have a diagnosis of bipolar disorder?

I am Roisin Turner, a Trainee Clinical Psychologist who is studying at Lancaster University. I am doing a research project exploring people's views of their psychiatric diagnosis specifically bipolar disorder.

Taking part in the research will involve being interviewed once for approximately 60-90 minutes. If you decide to take part, you can claim your travel expenses (up to £20) back from the university.

If you have received a diagnosis of bipolar disorder and would like to take part or you have any questions, please contact me **before [date to be inserted]**:

☎ [dedicated mobile number supplied by Lancaster University for the purposes of the research to be inserted]

🖱 [redacted]@lancaster.ac.uk

✉ Roisin Turner
FREEPOST: RTAU-SYXU-YCZZ
Doctorate in Clinical Psychology

Furness Building
Lancaster University
Lancaster
LA1 4YD

Appendix B

Letter to potential participants from the [redacted]

Health and Medicine | LANCASTER UNIVERSITY

26th July 2014

Dear [redacted] Member,

I am writing to ask if you would like to take part in a research study that will be taking place shortly. The research is being carried out by a trainee Clinical Psychologist, Roisin Turner, who is studying at Lancaster University. She is interested in exploring people's views of receiving a diagnosis of bipolar disorder. To participate in the research you must have been diagnosed with bipolar disorder by a psychiatrist.

The research will involve being interviewed once for approximately 60-90 minutes. Roisin will ask you questions about what you thought was helpful or not helpful about your diagnosis. She will not ask you about difficult life events you may have experienced before receiving the diagnosis, unless you think they are important in understanding your experience.

The [redacted] is inviting participation in the research project from people who have a diagnosis of bipolar and who have previously agreed that they would like to participate in research. I will be supervising Roisin alongside another psychologist within the clinical psychology department at the university. Other staff at the [redacted] will not be involved in analysing the interview data. Roisin has included an information sheet for you to read, and she is happy to answer any questions you have. If you decide to take part, you can claim your travel expenses (up to £20) back from the university.

If you would like to take part or you have any questions, please contact Roisin **before [date to be inserted]**:

☎ [dedicated mobile number supplied by Lancaster University for the purposes of the research to be inserted]

🖱 [redacted]@lancaster.ac.uk

✉ Roisin Turner
FREEPOST: RTAU-SYXU-YCZZ
Doctorate in Clinical Psychology
Furness Building
Lancaster University
Lancaster
LA1 4YD

Yours sincerely,

Professor [redacted]
Clinical Psychologist

Appendix C

Participant Information Form

Participant Information Sheet

Living with a diagnosis of bipolar disorder: A narrative analysis

My name is Roisin Turner and I am carrying out this research as a trainee Clinical Psychologist in the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The goal of this study is to explore people's experience of psychiatric diagnosis, specifically bipolar disorder. I am interested in hearing from people who have received a diagnosis of bipolar disorder and would like to ask their views about this.

Why have I been approached?

You have been asked to take part because you have received a diagnosis of bipolar disorder.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. If you want to take part and change your mind before your interview information is analysed then your interview information will not be used.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to contact me either by telephone, post or email. I can answer any questions you may have and we can arrange a day and time to meet for the interview. The audio-recorded 60-90 minute interviews will take place in either at Lancaster University or if you prefer at your home.

Will my information be confidential?

The information you provide is confidential. The information collected for this study will be stored securely and only the researchers conducting this study will have access to this information:

- Audio recordings will be destroyed and/or deleted as soon as possible after the thesis has been examined.
- The signed consent forms and completed demographic information sheets (which asks about your age, gender, when you had received your diagnosis etc.) will be kept in a locked cabinet.

- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- At the end of the study, the consent forms, demographic information sheets and transcripts will be scanned, encrypted and saved. The data will then be transferred and saved securely by the Research Coordinator in a password-protected space on the university server. This will be kept securely for a total of ten years by Lancaster University, and then deleted/destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Direct quotations from your interview may be used in the reports or publications from the study, but your name will not be attached to them.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a thesis as part of my training at the university and may be submitted for publication in an academic or professional journal.

Are there any risks?

There are no risks anticipated with taking part in this study. However, if you experience any distress following participation you are encouraged to inform me. If I am concerned about you the interview may be terminated and I would speak to another professional at the university for advice and support. At the end of the interview I will give you a copy of the contact list of resources provided at the end of this sheet should you require support following the interview.

Are there any benefits to taking part?

There are no direct benefits to taking part but you may find it interesting. Your views may help to shape how professionals think about psychiatric diagnosis and how this is provided for other people in the future.

Who has reviewed the project?

This study has been reviewed by Lancaster University's Faculty of Health and Medicine Research Ethics Committee and approved by Lancaster University Research Ethics Committee.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact me:

Roisin Turner
Doctorate in Clinical Psychology

Furness Building
Lancaster University
Lancaster
LA1 4YD

[redacted]@lancaster.ac.uk

Telephone: [dedicated mobile number supplied by Lancaster University for the purposes of the research to be inserted]

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Research Director: Dr [redacted]
Tel: (01524) [redacted]
Email: [redacted]@lancaster.ac.uk
Doctorate in Clinical Psychology
Lancaster University
Lancaster
LA1 4YD

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Head of the Division of Health Research: Professor [redacted]
Tel: (01524) [redacted]
Email: [redacted]@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YD

Associate Dean for Research: Professor [redacted]
Tel: (01524) [redacted]
Email: [redacted]@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YD

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Bipolar UK: 020 7931 6480
Rethink: 0300 5000 927
Mind: 0300 123 3393
Samaritans: 08457 909090
SANE: 0845 767 8000

Appendix D

Consent Form

Consent Form

Living with a diagnosis of bipolar disorder: A narrative analysis

We are asking if you would like to take part in a research project exploring your experience of psychiatric diagnosis, specifically bipolar disorder.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Roisin Turner.

Please place your initials in box after each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be kept until the research project has been examined. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐
7. I understand that the information from my interview will be combined with other participants' responses, anonymised and may be published. ☐
8. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with her research supervisor. ☐
10. I consent to Lancaster University keeping an electronic anonymised copy of my consent form, demographic information and interview transcripts for 10 years after the study has finished. ☐
11. I consent to take part in the above study. ☐

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Name of Participant____________________

Signature______________________________ **Date** _____________

Name of Researcher____________________

Signature______________________________ **Date** _____________

Appendix E

Demographic Information Form

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Demographic Information

Living with a diagnosis of bipolar disorder: A narrative analysis

Please answer the following questions as accurately as you can:

How old are you? _____________ years _____________ months

What is your gender? Male ☐ Female ☐

What is your ethnicity? __________________________

Approximately how long ago did you receive your diagnosis of bipolar disorder? __________________________

Do you have another psychiatric diagnosis other than bipolar disorder?

☐ No ☐ Yes - If so, please specify ___________________________

Please provide details of your GP or Care Coordinator (they will be contacted prior to interview to enquire about potential risk issues, and may be contacted following interview if there are concerns about you. You will be informed of this should this need to happen):

Name ____

Address: ____

Telephone number: ____

Appendix F

Interview Schedule

Introduction of interviewer

Hello, my name is Roisin and I would like to talk to you about your experiences of receiving a psychiatric diagnosis of bipolar disorder. I won't ask you questions about difficult life experiences you may have had, but if you feel it is important to talk about this to help me understand your diagnosis, then you can. If I don't word a question right or you don't understand what I have asked and you need me to ask it another way please just tell me.

Initial questions

How are you today? What have you been doing today/this week? When I write up the research I want to use another name for you so your identity is kept confidential – what name would you like? Please tell me about your experience of being diagnosed with bipolar disorder.

Main questions	Additional questions	Clarifying questions
Tell me about events leading up to your diagnosis. What messages did you receive at the time of diagnosis? How did you view your diagnosis at the time? What was that like? What did you think about it? Has that changed at all? What has life been like since receiving your diagnosis (family, friends, work)? Have you found anything helpful about receiving a diagnosis? Have you found anything unhelpful? If you could change something about your diagnosis experience what would that be? If this part of your life was a chapter of a book, what would the title be? What have been the key events in your life that have contributed to your views? Is there anything else you want to talk about relating to your diagnosis?	Why? What happened when you received your diagnosis? What feelings did you experience? Have you noticed any changes since then? What was most powerful/important thing you took away from your experience?	Can you tell me a little on this? Can you tell me anything else? Can you give me some examples?

Debriefing Sheet

Debriefing Sheet

Living with a diagnosis of bipolar disorder: A narrative analysis

Thank you for taking part in the research. The goal of this study was to explore service users' experience of psychiatric diagnosis, specifically bipolar disorder and hearing what you thought about your diagnosis and how helpful it has been. Your views may help to shape how professionals view diagnosis and how this is provided for people in the future.

What will happen to your information?

The information you provided is confidential, and will be stored securely. Only the researchers conducting this study will have access to this information. The typed version of your interview will be made anonymous by removing any identifying information including your name. Direct quotations from your interview may be used in the reports or publications from the study, but your name will not be attached to them.

What will happen to the results?

The results will be summarised and reported in a thesis research project as part of my training at the university and may be submitted for publication in an academic or professional journal.

Where can I obtain further information about the study if I need it?

If you have any further questions about the study or would like a copy of the research once it is completed, please contact me:

Roisin Turner
Doctorate in Clinical Psychology
Furness Building
Lancaster University
Lancaster
LA1 4YD

Email: [redacted]@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Research Director: Dr [redacted]
Tel: (01524) [redacted]
Email: [redacted]@lancaster.ac.uk
Doctorate in Clinical Psychology
Lancaster University
Lancaster
LA1 4YD

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Head of the Division of Health Research: Professor [redacted]
Tel: (01524) [redacted]
Email: [redacted]@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YD

Associate Dean for Research: Professor [redacted]
Tel: (01524) [redacted]
Email: [redacted]@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YD

Thank you for taking the time to read this debriefing sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Bipolar UK: 020 7931 6480
Rethink: 0300 5000 927
Mind: 0300 123 3393
Samaritans: 08457 909090
SANE: 0845 767 8000

Ethical Committee Application Form

Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research

1.1 Instructions

1. Apply to the committee by submitting
   - ✓ The University's Stage 1 Self-Assessment Form (standard form or student form) ***and*** the Project Information & Ethics questionnaire. These are available on the Research Support Office website: LU Ethics
   - ✓ The completed FHMREC application form
   - ✓ Your full research proposal (background, literature review, methodology/methods, ethical considerations)
   - ✓ All accompanying research materials such as, but not limited to,
     1) Advertising materials (posters, e-mails)
     2) Letters of invitation to participate
     3) Participant information sheets
     4) Consent forms
     5) Questionnaires, surveys, demographic sheets
     6) Interview schedules, interview question guides, focus group scripts
     7) Debriefing sheets, resource lists
2. Submit all the materials electronically as a **SINGLE** email attachment in PDF format. Instructions for creating such a document are available on the FHMREC website (http://www.lancs.ac.uk/shm/research/ethics/).
3. Submit one collated and signed paper copy of the full application materials. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.
4. Committee meeting dates and application submission dates are listed on the research ethics committee website http://www.lancs.ac.uk/shm/research/ethics. Applications must be submitted by the deadline stated on the website, to:

   Diane Hopkins
   Faculty of Health & Medicine
   B03, Furness College
   Lancaster University, LA1 4YG
   d.hopkins@lancaster.ac.uk

5. Attend the committee meeting on the day that the application is considered.

1. Title of Project: **Living with a diagnosis of bipolar disorder: A narrative analysis**
2. If this is a student project, please indicate what type of project by ticking the relevant box: ☐ PG Diploma ☐Masters dissertation ☐MRes ☐MSc ☐ DClinPsy SRP

☐ PhD Thesis ☐PhD Pall. Care/Pub. Hlth/Org. Hlth & Well Being ☐MD
☑ **DClinPsy Thesis**

☐ Special Study Module (3rd year medical student)

3. Type of study
☑ **Involves direct involvement by human subjects**

☐ Involves existing documents/data only. Contact the Chair of FHMREC before continuing.

Applicant information

4. Name of applicant/researcher:
Roisin Turner

5. Appointment/position held by applicant and Division within FHM:
Trainee Clinical Psychology (Health and Medicine - Doctorate in Clinical Psychology)

6. Contact information for applicant:

E-mail: [redacted]**@lancaster.ac.uk** Telephone: [redacted]

Address: **Department of Clinical Psychology, Furness College, Lancaster University**

7. Project supervisor(s), if different from applicant:

Name(s): **Dr** [redacted] **/ Professor** [redacted]

E-mail(s): [redacted]**@lancaster.ac.uk /** [redacted]**@lancaster.ac.uk**

8. Appointment held by supervisor(s) and institution(s) where based (if applicable):

9. Names and appointments of all members of the research team (including degree where applicable)

The Project

NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. Summary of research protocol in lay terms (maximum length 150 words).

There are limited research studies exploring people's views regarding their own mental health, particularly using qualitative methods. The Division of Clinical Psychology (British Psychological Society, 2013) highlighted the importance of service user views with this debate. They highlighted that often service users find that diagnosis can have some benefits, for example, offering assurance that they are not to blame for their difficulties (e.g. Bringewatt, 2013). Dinos et al (2004) found that service users who had received a psychiatric diagnosis disclosed negative experiences such as stigma and discrimination. However some also expressed relief in receiving a diagnosis, and some thought that through acceptance of their diagnosis they as a consequence were better adjusted.

The aims of this research are to readjust this imbalance and explore service users narratives regarding their journey to and following receiving a diagnosis of bipolar disorder. This will enable professionals to gain a greater insight into how useful or unhelpful psychiatric diagnosis is for service users, and adds service users' voices to the debate of the current system of diagnosis.

11. Anticipated project dates

Start date: **August 2014** End date: **May 2015**

12. Please describe the sample of participants to be studied (including number, age, gender):

The target sample for the research is 10-12 male and female adults aged over 18 years who have received a psychiatric diagnosis of bipolar disorder. This sample size is appropriate for the purposes of this research, which is to obtain views about the diagnosis process through in-depth interviews.

13. How will participants be recruited and from where? Be as specific as possible.

Recruitment will be phased so that initially only those who are on the database and who receive the [redacted] newsletter will be invited to take part. This process will prevent an excess number of potential participants being asked. The [redacted] will inform potential participants via the July 2014 newsletter edition that a study will be taking place soon. They are asked to contact the [redacted] if they are interested, and once ethical approval has been gained, these potential participants will be contacted by the researcher. Once ethical approval has been gained, information regarding the study will be sent out via the September 2014 edition of the newsletter. Participants who are able to attend a face-to-face interview will be prioritised. For those participants who provide a telephone number, the researcher will contact them to explain the study, and send a letter (as approved by Professor [redacted], Appendix B) and Information Sheet (Appendix C) to them. Those who provide an email or postal address will also be sent this information, and they will be asked to contact the researcher if they wish to take part. The researcher will offer time to explain the study further face-to-face or via telephone if they wish.

A second phase of recruitment will be used should there be a lack of volunteers by mid October 2014. This will involve sending the letters out to people listed on the [redacted] database. Although these people may also receive the newsletter, it cannot be guaranted that they have read the newsletter as this is sent to members via email. They will be asked to contact the researcher before the start of November 2014 should they wish to participate.

If there is still a lack of volunteers by the start of November 2014, then a third phase will be employed to recruit via north-west support group attendees. This would include [redacted], which has over 12 support groups within the north west. This will involve sending information to the organisers to pass on to the attendees with the researcher's contact details (Appendix A).

14. What procedure is proposed for obtaining consent?

Initial contact with service users will be done via a letter (Appendix B) and Information Sheet (Appendix C) to explain the study, and they will be asked to contact the researcher if they wish to take part. The researcher will offer time to explain the study further face-to-face or via telephone if they wish. The researcher will explain confidentiality and anonymity as highlighted on the consent form (Appendix D). Once they have verbally agreed to take part, they will be asked to complete the consent form. An interview date and time will then be agreed. The participants have a right to withdraw at any point until their interview data has started to be analysed.

15. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

The main ethical issues are the use of adult participants who will be talking about parts of their life that may be upsetting to discuss. In attempt to prepare potential participants, full information regarding the study will be provided verbally and in written form for the participants. This will include information regarding withdrawal of consent and who to contact should they not be satisfied with any aspect of the process.

It is acknowledged that participants may experience some unanticipated emotional discomfort distress during or after the interview. Prior to the interview the participants will be asked about their current mood, and whether they feel they think participating in the research may impact upon their mental health. They will also be asked to provide their General Practitioner (GP) or Care Co-ordinator contact telephone number. They will be contacted prior to interview to check whether there are any potential risk issues. The limits of confidentiality will be explained to participants in that these professionals will only be contacted during or after interview if the researcher thinks that there is a serious and /or immediate risk of harm either to themselves or another person. If the researcher has concerns of any matter, they will initially contact their supervisor.

The participant will be offered a telephone call from the researcher the day after the interview to ask if they have any questions or comments following the interview.

Participants will also be provided with a debriefing sheet (Appendix G) which will list contact telephone numbers for support services should they require additional support following the interview.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).

Rooms at the university are available for interviews, or the applicant can interview the participants at their home if they prefer. If the participant wishes to be interviewed at home, the [redacted] Foundation Trust Lone worker Policy (June 2013) will be adhered to. This involves ensuring that my supervisors are aware of when and where interviews are taking place, carrying an ID badge (please note: not wearing an NHS ID badge), arranging interviews during daylight hours, and having emergency contact numbers saved onto the mobile phone. More specifically, a colleague will be informed when the interviews will take place, and the interview locations will be made known if required. The address of the interview will be written in a sealed envelope; this will only be opened in the event that the researcher does not make contact at an agreed time when the interview has finished. If contact is made then the researcher will retrieve and destroy the address. The researcher will telephone them when the interview is finished, with an agreement that if no telephone call comes by a set time they will try to ring the researcher and then ring the police if they cannot get through.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There are no direct benefits to taking part but the participants may find it interesting. Their views may help to shape how professionals think about psychiatric diagnosis and how this provided for other people in the future.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

Potential costs for the research are travel expenses for service users. Lancaster University will refund public travel costs or up to £20 petrol costs per service user.

19. Briefly describe your data collection and analysis methods, and the rationale for their use

The interviews will be analysed using Narrative Analysis as this allows individuals to tell their stories and themes to be developed from this. The research will follow an inductive analysis, meaning that the data will help develop a theory rather than looking for data to prove or disprove a theory, which will reduce bias in the coding of the data. Analysis in narrative studies does not simply look at the content to which language refers, it asks why was the story told *that* way? (Riessman 1993). Narrative analysis links well into theories of self and identity, and exploring lived human experiences (Crossley, 2000).

The interview data will be listened to and transcribed by the researcher. The data will be analysed by the researcher with input from the supervisors to discuss the themes identified. Analysis will involve the transcriptions being read repeatedly in order to identify recurrent and salient themes. These themes will be refined as this process continues in order to ensure that they are consistent with the interview data.

In terms of confidentiality, the participant's information will be anonymised from start with use of a code number, and the participants will be asked to provide another name that can be uses as an identifier within the report. Confidentiality will only be breached in exceptional circumstances i.e. if it is felt that the service user is at risk of harm to themselves or others, and this information with be shared with my supervisors. The participants have a right to withdraw at any point and they will be provided with their own code number so as to keep confidentiality if they wish to withdraw. A codebook matching real names with pseudonyms and codes will be kept in a encrypted file which is password protected, in line with Data Protection requirements. Only the researcher will have record of participant's real names for the purpose of providing a summary of the research unless they wish otherwise.

20. Describe the involvement of users/service users in the design and conduct of your research. If you have not involved users/service users in developing your research protocol, please indicate this and provide a brief rationale/explanation.

The research proposal was presented to the [redacted] service user group in June 2014, who provided feedback on the proposal including the method, recruitment process and interview schedule.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

The typed transcripts will be stored in a locked filing cabinet by the researcher and once the thesis has been submitted they will be scanned, encrypted and saved. The data will then be transferred and saved securely by the Research Coordinator in a password-protected space on the university server. This will be kept securely for a total of ten years by Lancaster University, and then deleted/destroyed.

22. Will audio or video recording take place? ☐ no ☑**audio** ☐video

If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

All interviews will be digital audio-recorded and transcribed in full. The audio recordings will be destroyed and/or deleted as soon as possible after the thesis has been examined, as it is not possible to encrypt the portable devices the interviews will be recorded on. The typed transcripts will be encrypted, password protected and stored securely by the researcher and once submitted the paper documents will be scanned, encrypted and saved. The data will then be transferred and saved securely by the Research Coordinator in a password-protected space on the university server. This will be kept securely for a total of ten years by Lancaster University, and then deleted/destroyed.

23. What are the plans for dissemination of findings from the research?

Following submission, a separate report will be disseminated to participants unless they have specified that they do not wish to receive information regarding the study. A copy of the research will be disseminated to the researchers at the [redacted]. As a condition from the university, the findings will be presented at a presentation day at the university in 2015. The authors will also look for opportunities to disseminate at national conferences, and will submit the paper for publication in a journal relevant to clinical psychology.

24. What particular ethical problems, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek advice from the FHMREC?

If the researcher has ethical concerns of any matter, they will initially contact their supervisor to discuss this. The limits of confidentiality will be explained to participants in that professionals will only be contacted if the researcher thinks that there is a serious and /or immediate risk of harm either to themselves or another person.

Signatures: Applicant: ……………………..……………………......................................

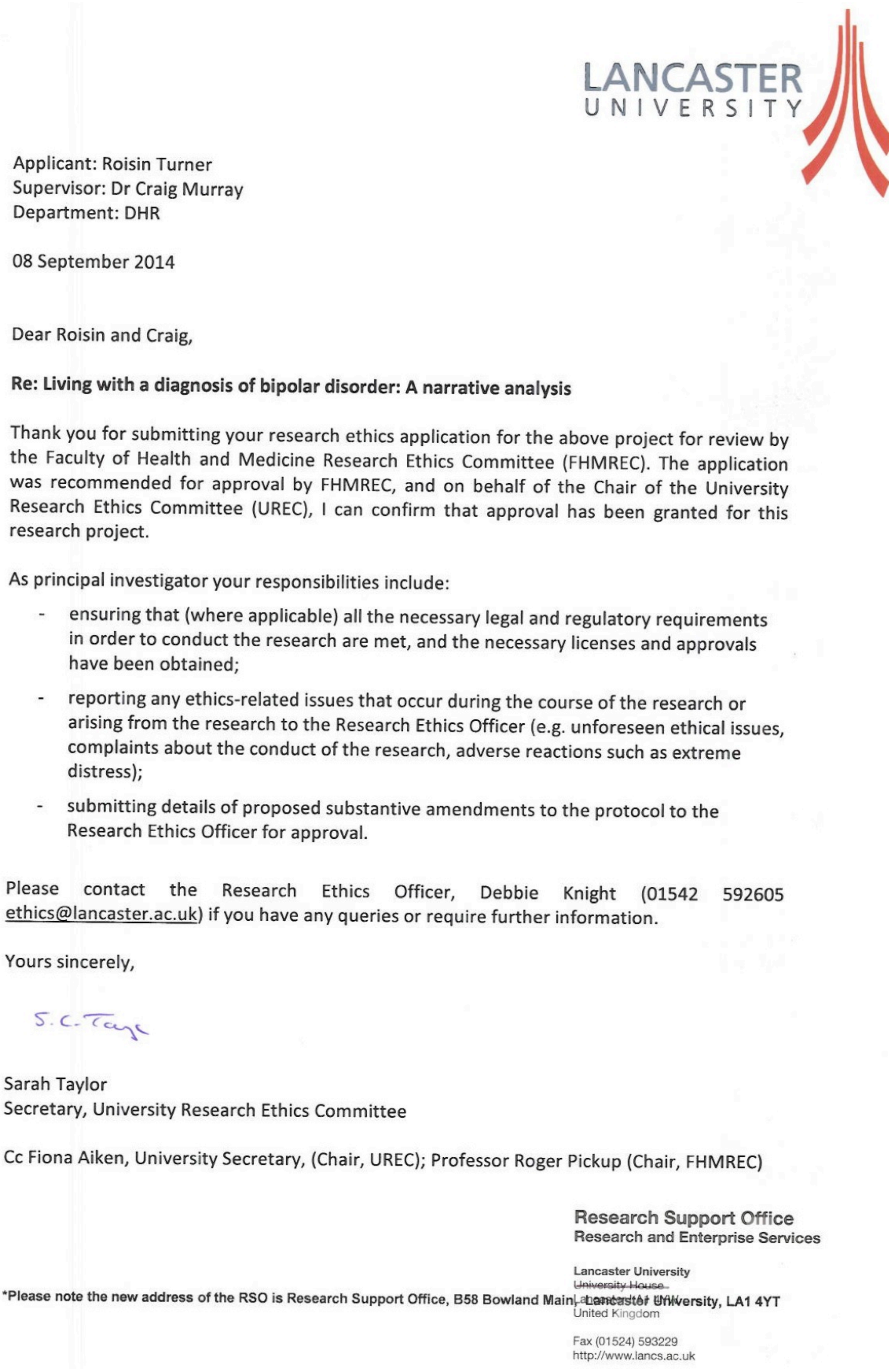
Date: …………………………………………………..

Project Supervisor* (if applicable): …………………………………….................

Date: …………………………………………………..

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

Ethical Committee Approval Letter



Applicant: Roisin Turner
Supervisor: Dr Craig Murray
Department: DHR

08 September 2014

Dear Roisin and Craig,

Re: Living with a diagnosis of bipolar disorder: A narrative analysis

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

S. C. Tayl

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Fiona Aiken, University Secretary, (Chair, UREC); Professor Roger Pickup (Chair, FHMREC)

Research Support Office
Research and Enterprise Services

Lancaster University
~~University House~~
[illegible]
United Kingdom

Fax (01524) 593229
http://www.lancs.ac.uk

***Please note the new address of the RSO is Research Support Office, B58 Bowland Main, Lancaster University, LA1 4YT**