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"Twenty wasted years"

Exploring the experience of misdiagnosis within Bipolar Type Two disorder

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ABSTRACT

Bipolar Type Two disorder (BP- II) is a mental health disorder that is frequently misdiagnosed as depression due to the shared predominant symptom of recurrent, extended periods of depression and unrecognized hypomanic symptoms. Previous quantitative research demonstrated that misdiagnosis significantly impaired individual's wellbeing and heightened suicide risk. However, the experience of misdiagnosis from a qualitative approach had not yet been considered, therefore, the aim of the current research was to explore the experience and impact of misdiagnosis within BP- II disorder. A thematic analysis was performed on online bipolar support forums that discussed the experiences of misdiagnosis. The analysis revealed that misdiagnosis left participants with inappropriate and unsuccessful treatment. The ineffective treatment increased suicidal ideation and action, feelings of hopelessness and inflicted instability throughout the participant's lives. The study also identified that participants were predominantly misdiagnosed with depression and frequently remained misdiagnosed for several years and in some cases decades. In order to combat the prevalence of misdiagnosis, the present study supported the utilisation of hypomanic screening through the diagnostic process as the recognition of hypomanic symptoms is key to separating BP-II disorder from depression.

KEY WORDS:	BIPOLAR TYPE TWO	BIPOLAR DISORDER	MISDIAGNOSIS	DIAGNOSIS	HYPOMANIA

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Chapter One: Introduction

Bipolar disorder is a complex, severe psychiatric disorder categorized by unusual shifts in mood and energy (Calvo, Llewellyn-Jones, Cervesi, Sareen & Moreno, 2016). Bipolar disorder contains three categories and the current study focused on bipolar disorder type two (BP- II) which is frequently misdiagnosed as various depressive disorders due to the shared predominant symptom of recurrent, extended periods of depression (Miller, Johnson & Eisner, 2009). Previous research has demonstrated that misdiagnosis within BP- II disorder significantly increases suicide risk and negatively impacts employment, finances, substance abuse and social functioning (McCraw, Parker, Graham, Synnott & Mitchell, 2014). Although the prevalence and severity of misdiagnosis has been demonstrated, the individual experience and impact of misdiagnosis within BP- II disorder has yet to be considered.

Firstly, the historical background of BP- II will be discussed as it highlights one of the key issues that still plays a role in misdiagnosis today; lack of recognition. Hippocrates also known as “The Father of Medicine” was responsible for the earliest discovery of the symptoms associated with bipolar disorder and created the terms melancholy and mania (Kasper & Hirschfeld, 2005). The word melancholy derived from the Ancient Greek word *melas* meaning 'black' and *chole* meaning 'bile' because he believed that depression resulted from an excess of black bile (Angst & Marneros, 2001). Hippocrates described melancholia as a condition associated with an unshakeable sadness, lack of appetite, social isolation, sleeplessness, irritability and aggressive behaviour that could sometimes lead to suicide (Jackson, 1978). Whereas mania related to the Ancient Greek word *menos* meaning 'spirit, force and passion' and was believed to result from an excess of yellow bile (Laios, Tsoukalas, Kontaxaki, Karamanou & Androutsos, 2014).

The earliest known written record of a suggested relationship between depression and mania can be dated back to Ancient Greece specifically to Aretaeus of Cappadocia, a physician and philosopher of the first century who was often described as the “Father of Mania” (Marneros, 2001). He described mania as *"Furor, excitement and cheerfulness"* and melancholia as *“Torpid, dull, sorrowful"* (Mitchell, 2016) and even reported on the shifts between phases of melancholy and mania.

"Some patients after being melancholic have fits of mania..." "..they

show off in public with crowned heads as if they were returning victorious from the games; sometimes they laugh and dance all day and all night" "…he becomes, at the end of the attack, languid, sad, taciturn, he complains that he is worried about his future, he feels ashamed" (Roccatagliata, 1986).

However, Aretaeus's suggestion that both patterns of behaviour resulted from the same disorder did not gain currency until the modern era (Thomas & Grey, 2016). Examples of recognition could be seen during the 19th century by two French doctors Jules Baillarger (1809–1890) and Jean-Pierre Falret (1794–1870) who individually presented portrayals of bipolar disorder to the Academeie de Medicine in Paris (Tondo, Vazquez & Baldessarini, 2017). Balligarger described bipolar disorder as *folie à double forme* (dual-form insanity) (Baillarger, 1854), whereas Falret described it as *folie circulaire* (circular insanity) (Falret, 1854) and both were credited for discovering bipolar disorder (Tondo, Vazquez & Baldessarini, 2017). Ground breaking discoveries in bipolar disorder were also aided by pioneers such as German psychiatrist Karl Leonhard during the 20th Century. In 1957 Leonhard coined the term 'bipolar' after proving that bipolar could be distinguished as a separate disorder to depression (Leonhard, 1957). Leonhard's work gained additional support in 1966 from Angst and Perris's research which further demonstrated that bipolar disorder and depression could be differentiated in terms of clinical appearance, family history, evolution and response to treatment (Angst, 1966; Perris, 1966).

Although bipolar disorder was gaining recognition, the symptoms reflected the classic bipolar otherwise known as bipolar type one (BP-I) and little evidence suggested acknowledgement of BP-II. The first research to recognise BP- II as a distinct disorder was by Dunner, Gershon and Goodwin, (1976). They observed that whereas BP- I was categorised through its symptoms of depression and mania, the latter of which was associated with a number of symptoms such as; feelings of euphoria, lack of inhibitions and sleep, racing thoughts, fast talking, risk taking, irritability and severe psychotic features that can require hospitalisation (Machado- Vieira et al., 2017). In comparison, the symptom of hypomania was perceived to be a milder form of mania, often leaving patients in elevated or agitated moods. These symptoms were rarely severe and therefore did not require hospitalisation or indicate any presence of psychotic symptoms (Grande, Berk, Birmaher & Vieta, 2016). Upon this discovery Dunner, Gershon and Goodwin (1976) suggested that the symptoms of hypomania and depression did not currently align with BP- I or any other known disorder at the time. It was proposed that patients experiencing symptoms of both recurrent depression and hypomania should be classed with a separate disorder known as BP- II. The researchers were keen to make clear distinctions between the two disorders of BP- I and BP- II through the

separation of hypomania and mania. Furthermore, they advised that BP- II should also be distinguished as a separate disorder from unipolar depression which was characterised by a history of frequent depressive periods as it could not account for the symptoms of hypomania. Although BP-II disorder had finally been acknowledged it was clear that there was a high potential for misdiagnosis due to unrecognised or overlapping symptoms with other disorders (Miller, Johnson & Eisner, 2009). In light of this, perhaps the lack of historical mention of BP-II disorder could be excused as the disorder still struggles to be recognised up to the present day despite advances in understanding and technology (Benazzi, 2007).

BP- II disorder was officially recognised by the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) with its publication in 1994 (DSM-IV, 1994). The DSM is a collection of mental health disorders and their symptoms. It is a guide that is used worldwide by clinicians and psychiatrists to assist the assessment of their patients' mental disorders, case formulation and treatment planning. The current version of the DSM is the DSM 5 which requires patients to meet the following criteria to receive a diagnosis of BP- II disorder; the presence or history of one of more major depressive episodes lasting at least two weeks and at least one hypomanic episode that lasts at least four days while causing significant distress or impairment to social, occupational or other important areas of functioning (American Psychiatric Association, 2013). However, Angst, (2013) argues that the DSM criteria for BP- II disorder is too rigid, suggesting that mental health symptoms are subjective, diverse and complex and that the overlap of these symptoms with other disorders only adds further complexity to diagnosing mental health conditions. Additionally, it has been suggested that other symptoms of BP- II disorder such as distress, impairment, episode duration and the length of suffering should all be taken into consideration during clinical assessments rather than rely on patients to tick predetermined boxes (Angst et al., 2012). The influences behind the production of the DSM must also be called into question as 69% of the DSM-5 task force members are reported to have financial ties to the pharmaceutical industry which could inflict bias and impact its ethical and moral standing (Cosgrove & Krimsky, 2012).

Despite the DSM-5's somewhat controversial nature, its significant influence on the perception and diagnosis of mental health disorders cannot be disputed (Guloksuz, Pries & Van Os, 2017). However, in the UK, clinicians and psychiatrists also refer to another diagnostic system known as the International Classification of Diseases (ICD-10) (WH0, 1992; Maldonado, González, Castillo, & Jaurez, 2011). In comparison to the DSM-5, it could be argued that the ICD-10 is a more trustworthy tool as it

is produced by the World Health Organisation whose mission is to build a better, healthier future for people all over the world (WHO, 1992). The ICD-10 has been broadly distributed throughout many countries and is even available free on the internet, a stark comparison to the hefty cost that goes along with purchasing a copy of the DSM-5 (American Psychological Association, 2018). But despite the ICD-10's intentions, it is debatable how useful it is in the issue of misdiagnosis within BP- II disorder. Currently, the ICD-10 does not recognise BP- II as a separate disorder and instead lists it under 'Bipolar affective disorder with hypomanic symptoms' amongst several other variations of bipolar disorder (WH0, 1992). Regardless of this, the Division of Clinical Psychology have argued that both of the current classification systems such as the DSM-5 and ICD-10 have significant limitations such as; subjectivity, limitations in validity and reliability, dominance of the disease model, ethnocentric bias and decontextualisation. Proposing that a new multifaceted diagnostic approach should be adopted. One that aims to understand the complexity and subjectivity of the human experience but also acknowledges the role of context in distress and behaviour (Awenat et al., 2013). Consequently, The National Institute of Mental Health (NIMH) have also supported a dramatic shift away from the current diagnostic approach claiming that "patients with mental health disorders deserve better". The NIMH have proposed that diagnostic process should be more objective and employ scientific methods such as; cognitive testing, brain scans and genetic predisposition (National Institute of Mental Health, 2018).

Although these advances in diagnosing could help to combat misdiagnosis within BP- II disorder, Angst, (2013) argues that the biggest challenge facing misdiagnosis within BP- II disorder is the lack of hypomanic screening and suggests that misdiagnosis will continue until this is resolved. Many support the notion that the unrecognised hypomania is a significant influence on misdiagnosis within BP- II disorder (Singh & Rajput, 2006; Miller, Johnson & Eisner, 2009). BP- II disorder is at particular risk of being misdiagnosed for depressive disorders due to the overlap in the predominant symptoms of extended, recurrent periods of depression (Miller, Johnson & Eisner, 2009). These depressive episodes appear to be considerably more problematic and apparent to both patient and clinician, while the hypomanic symptoms are all too often unrecognised therefore increase the rate of misdiagnosis within BP- II disorder (Kuppili, Yadav & Pattanayak, 2017). This was supported by a longitudinal study spanning 20 years that demonstrated patients with BP- II disorder experienced a significant dominance of depressive symptoms, totalling them to just over a decade in comparison to only experiencing hypomanic symptoms over four months (Judd et al., 2003). Switches into hypomanic episodes were

frequently interpreted as a recovery or high and often seen in a positive light as they were not as obvious or harmful in comparison to the mania experienced by those with BP- I disorder (Angst, 2017). It is important to note that not all hypomanic symptoms are positive, however, unfortunately negative symptoms of hypomania such as irritable mood and reduced sleep are often interpreted as further evidence for depression (Chen et al., 2016). Angst, (2013) argues that the current diagnostic systems are not currently capable of successfully separating BP- II disorder from depressive disorders, suggesting that up to 40% of those diagnosed with Major Depressive Disorder (MDD) have BP- II and stands by the notion that many will continue to be misdiagnosed until hypomanic screening is put in place (Angst, 2013). Further, hypomanic screening has successfully recognised hypomanic symptoms in previously misdiagnosed depressed patients (Benazzi & Akiskal, 2003). Thus, it is clear that the current diagnostic systems have many limitations and arguably fail to identify hypomanic symptoms which contribute to the high levels of misdiagnosis within BP- II disorder (Angst, 2013; Awenat et al., 2013). The experience of misdiagnosis will now be discussed in relation to its prevalence, personal impact and economic burden.

Studies have shown that misdiagnosis is a highly prevalent and prolific issue within BP disorder, suggesting up to 70% of individuals with bipolar disorder are initially misdiagnosed (Hirschfeld, Lewid & Vornik, 2003). Furthermore, it has been proposed that more than one third of patients remain misdiagnosed for ten years or more and on average patients remain misdiagnosed for around five to seven years (Singh & Rajput, 2006). Although the longevity of misdiagnosis has been debated, other studies suggest it takes thirteen years on average to receive a correct diagnosis of bipolar disorder (Tondo, Visioli, Preti, & Baldessarini, 2014). Additionally, Mosolov et al., (2014) found that on average it took participants fifteen years to obtain the correct diagnosis of BP- II from the initial onset of symptoms. Delays of this length in diagnosis can have a significant impact for the patient, effecting their overall prognosis and negatively impacting their response to treatments (Kapczinski et al., 2014). Research has suggested for each year of incorrect treatment there is a 10% less likelihood of recovery (Lish et al., 1994). Another study found that 35.9% of BP- II participants had been misdiagnosed with a depressive disorder and were incorrectly medicated with antidepressants (Mosolov et al, 2014). These findings are extremely troubling as it has been repeatedly shown that the sole treatment of antidepressants can increase rapid cycling and suicidal ideation (Undurraga, Baldessarini, Valenti, Pacchiarotti, & Vieta, 2012). Misdiagnosis leaves patients at a significant risk as having the disorder alone increases patients suicide risk to 20-30 times greater than the general population (Pompili et al., 2013). Additionally, it has been consistently found that untreated bipolar disorder can impair social functioning, negatively impact employment, while increasing

risk for financial difficulties, substance abuse and morbidity rates (McCraw, Parker, Graham, Synnott & Mitchell, 2014).

Misdiagnosis does not only leave devastating consequences for the patients, it also causes a significant economic burden for society (Kleine-Budde et al., 2014). The financial toll refers to both direct costs such as: hospitalisation, medication/psychiatric services and indirect costs including: unemployment, sick days, caregiver burden, social welfare and criminal justice costs (Parker, 2012). It has been estimated that misdiagnosis within bipolar disorder costs the UK £2 Billion annually and 86% of this figure related to indirect costs (Gupta & Guest, 2002). However, this figure is considered to be severely underestimated as the study only reflected misdiagnosis within BP- I disorder. Currently there are no studies which have contemplated the economic burden of misdiagnosis within BP- II disorder as research has typically focused on BP- I or bipolar disorder as a whole. Nonetheless it has been consistently shown that misdiagnosis within bipolar disorder increases health care costs and that these costs then increase significantly if the patients are not treated with mood stabilisers (Hirschfeld & Vornik, 2005; Matza, Rajagopalan, Thompson & de Lissovoy, 2005). Unfortunately, this is frequent in BP-II as it is commonly misdiagnosed for depression therefore anti-depressants are prescribed as treatment (Undurraga, Baldessarini, Valenti, Pacchiarotti, & Vieta, 2012). Many studies have demonstrated that inappropriate prescriptions of antidepressants were significant factors in the economic costs in misdiagnosis as they increase rates of hospitalisation from surges of negative symptoms and heightened suicide risk (Birnbaum et al., 2003; Matza, Rajagopalan, Thompson & de Lissovoy, 2005, McCombs et al., 2007; Stang et al., 2006; Stensland et al., 2010). In order to reduce these healthcare costs, early diagnosis is crucial and also provides the essential and appropriate treatment for those with BP- II disorder (Kendall, Morriss, Mayo-Wilson & Marcus, 2014; Wong, 2011). Moreover, early diagnosis and treatment can improve a patients' long-term outcome (Kapczinski et al., 2014) by increasing employment opportunities, psychosocial functioning and reduces the risk of relapse (Joyce, Thompson & Marwaha, 2016). However, a small but growing area of research suggests that individual's responses to receiving a diagnosis of BP- II can vary drastically (Fisher, Manicavasagar, Sharpe, Laidsaar-Powell & Juraskova, 2017). Supporting the proposal that individual's reactions to mental health diagnosis are complex and capable of validating individual's symptoms or challenging identity (Kokanovic, Bendelow & Philip, 2013) and burdening individuals (Peterson and Madsen, 2017). Nonetheless, research investigating misdiagnosis has demonstrated that not all individuals receive a diagnosis to respond to, let alone obtain an early diagnosis and several patients turn to online support groups for help (Vayreda & Antaki, 2009; Nasrallah, 2015).

Online support groups can be defined as an online community which enable people affected by a common problem to discuss personal information anonymously, provide advice and emotional support (Potts, 2005; O'Keeffe & Clarke-Pearson, 2011). Such groups have been regarded as an important factor in coping with bipolar disorder since they provide both an outlet and platform for bipolar patients to discuss their emotions and share daily struggles (Bauer, Bauer, Spiessl & Kagerbauer, 2013). They have been recognised as a therapeutic tool for people experiencing mental health difficulties (Setoyama, Yamazaki, & Nakayama, K, 2011), as engagement with others can decrease distress (Barak, Dolev-Cohen, 2006) while increasing important psychological factors such as; well-being, self-confidence, empowerment, independence, control and promote social interactions (Barak, Boniel- Nissim & Suler, 2008). Research has shown that participation in online support groups could reduce self-stigma and increase the probability of participants seeking formal support. Although, it has been questioned as to whether these benefits are associated with the same factors that encourage an online user to actively participate (Lawlor & Kirakowski, 2014). It has also been suggested that online support groups can offer the same benefits as joining an offline support group. These benefits include: informational and emotional support, empathy, guidance and the ability to develop positive coping mechanisms (Coleman, Shah and Jain, 2015). Research using thematic analyses to explore the benefits of online support groups support these findings suggesting that they allow individuals to connect with others, share information and enable coping mechanisms (Attard & Coulson, 2012; Breuer & Barker, 2015). In comparison to offline support, the anonymity and asynchrony provided by online support groups has been shown to increase self-disclosure (Suler, 2013) as forums are perceived as a protected environment where users are able to freely express themselves without the fear of negative repercussions (Frye & Dornisch, 2010). Online support groups are also unique in their asynchronous communication which has also been shown to be emotionally cathartic and empowering for users (Setoyama, Yamazaki, & Nakayama, 2011). Nonetheless, participation also has potentially harmful consequences such as: developing dependence, promoting distance from in-person interaction and exposure to negative interactions online. (Barak, Boniel- Nissim & Suler, 2008). This has been supported by Lawlor & Kirakowski, (2014) who proposed that online support groups are a form of social avoidance which do not help to combat stigma. However, it is argued that the potential advantages of online support groups well outweigh the disadvantages (Conell et al., 2016).

Misdiagnosis is a significant issue within BP- II disorder that has devastating consequences for patient's immediate lives and future prospects (Undurraga, Baldessarini, Valenti, Pacchiarotti, & Vieta, 2012; Pompili et al., 2013; Kapczinski et al., 2014; McCraw, Parker, Graham, Synnott & Mitchell, 2014). Previous research on this topic has successfully highlighted the prevalence and effects of misdiagnosis on a large scale through quantitative methods, however, the individual experience of misdiagnosis has yet to be considered. The current study employed a qualitative approach with

the use of a thematic analysis to give a voice to the experience of misdiagnosis within BP- II disorder in order to gain an understanding into the personal impact of misdiagnosis, bring awareness to issue of misdiagnosis within BP- II disorder and highlight the need for support offline as well as online.

Chapter Two: Method

Design

The design of the study was qualitative as this allowed the participants experiences to be at the heart of the research (Austin & Sutton, 2014). The data was collected using open forums from internet support groups and analysed with a Thematic Analysis (Braun & Clarke, 2006).

Participants

The current study employed a qualitative approach which relied on the richness of the collected data rather than a predetermined number of participants (Braun & Clark, 2016). Consequently, the study could have used more detailed, in depth or impactful messages from fewer participants rather than numerous ambiguous messages from many participants. However, to ensure that the current study would have enough messages to perform a sufficient thematic analysis, previous research studies using thematic analysis on online forums were identified and a guideline of 100 messages was established (Jamison, Sutton, Mant & De Simoni, 2017; Kilby, 2014; Otway, 2016; Morris, Dalujski & Dy, 2016). Therefore, the current research study collected a total of 100 messages from forums based in online bipolar support groups. The messages were collected from participants who discussed personal experiences of misdiagnosis within BP- II disorder.

Materials

The materials consisted of a password protected computer with internet access and Microsoft Word so the required website support forums could be loaded and the thematic analysis could be conducted.

Data collection

An internet search was performed to locate the appropriate online forum for individuals effected by BP- II disorder. The relevant forums were found using the search engine Google and the search term ‘bipolar type two support groups’. While this search provided many results, two websites were chosen based on their fulfilment of the following criteria: a) containing open forums that did not require a sign up process therefore making it open and available to the public (British Psychological Society, 2017) and; b) the forum had a suitable level of activity, with threads having an average response rate of six messages meaning there would be sufficient data for the analysis.

After locating the appropriate forums, the next stage was to identify appropriate threads within the forums which were considered the most likely to provide content that could successfully contribute to fulfilment of the current study aim. To discover the desired threads a key word search was firstly conducted using the following words; ‘misdiagnosis’ and ‘misdiagnosed’. These terms were selected as they were believed to be simple, relevant and effective to locate threads which would provide appropriate content for the analysis to meet the study aims. Although this search did prove somewhat adequate it also produced many threads regarding individuals who had incorrectly been giving the misdiagnosis of BP- II disorder which were not congruent to the research aim. Therefore, the search terms were refined with ‘just diagnosed’ and ‘finally diagnosed’ to yield results of participants who discovered they had been misdiagnosed. From both search results 100 messages were collected that had been posted within a set time period of 12 months spanning from January 2017 to December 2017 and discussed the experience of misdiagnosis. The age of the participant could not easily be verified online therefore the current study could not realistically prevent under 18's participating in the research project (British Psychological Society, 2017). However, if it was made clear that a user was under the age of 18 i.e. stating their age, then their posts were omitted from the research. Once the appropriate threads were identified, they were

downloaded and stored on a password protected computer.

Method of Analysis

A thematic analysis was appropriate for the current study as it systematically identified, analysed and reported patterns of meaning, otherwise known as 'themes', across the data set which reflected the experience of misdiagnosis within BP- II disorder. As thematic analysis is qualitative it does not seek to implement formal guidelines with regard to the number of messages which should be included (Braun & Clark, 2016). Further, it is a flexible method which was suitable to analyse data from online forums (Braun & Clark, 2006; Jamison, Sutton, Mant & De Simoni, 2017; Kilby, 2014; Otway, 2016; Morris, Dalujski & Dy, 2016). Additionally, it must be recognised that thematic analysis is an umbrella term which represents varying approaches differing in philosophy and technique. For the current research a reflexive/organic thematic analysis was employed which is distinguishable from other thematic analyses due to its focus on the active role of the researcher, emphasis on depth of engagement with the data and importance of the process reflecting the understanding of the data (Braun & Clark, 2016). In addition to this, a reflective/organic thematic analysis is also distinctive as it is commonly utilised for social justice agenda's and to give voice to marginalised groups. This further strengthens the suitability of thematic analysis within the current research as it aims to voice the experience of those who have been misdiagnosed (Braun & Clark, 2016).

The thematic analyses was performed by following Braun and Clark's (2016) 6- phase process which will now be outlined. The first stage was to firstly 'become familiar with the data' this stage was vital as it allowed the researcher to become immersed in the data through repeated reading in order to become familiar with all aspects of the data. Active reading was also employed which comprised of searching for initial meanings and patterns in the data, making notes and listing preliminary ideas for coding. Following this, the second stage was to 'generate initial codes' which required the researcher to manually code the entire data set line by line. The researcher then went on to identify prominent or interesting features of the data, summarising them with a code by using a either a single word, short phrase or occasionally drawing out

key quotes from the data.

After codes were generated the third stage was to ‘search for themes’ which involved the researcher writing each code and a brief description onto post-it notes. Individual codes were then organised into groups by of potential themes by looking for patterns in the data. Once the potential themes were collated stage four required the researcher to ‘review the themes’ in a two-step progress. The first step required the researcher to assess whether the themes work in relation to the coded data. This allowed an opportunity to edit the themes by collapsing them together or spitting them into more specific themes or discard codes. When this was completed the second stage was to consider whether the themes worked in relation to the entire data set. This stage involved rereading the entire data set to determine whether the themes meaningfully captured the experience of misdiagnosis and ensure that the themes acknowledged the most important parts of the data in relation to the research question (Braun & Clark, 2012). When the researcher was satisfied that the themes sufficiently depicted the data, the fifth stage sought to ‘define and naming the themes’. This stage required the researcher to define what each theme was, explain the reason behind each theme and summarise the aspects of the data it attempted to capture. Naming the theme involved crafting theme names that were informative, concise and catchy. Quotes were also used as theme names when appropriate as they instantly portrayed a vivid sense of the theme (Braun & Clarke, 2012). Once the researcher had a complete set of comprehensive themes the final stage began. The sixth stage consisted of ‘producing the report’ in which the researcher developed a clear and detailed report that reflected the experience of being misdiagnosed supported by evidence from the data (Braun & Clark, 2006).

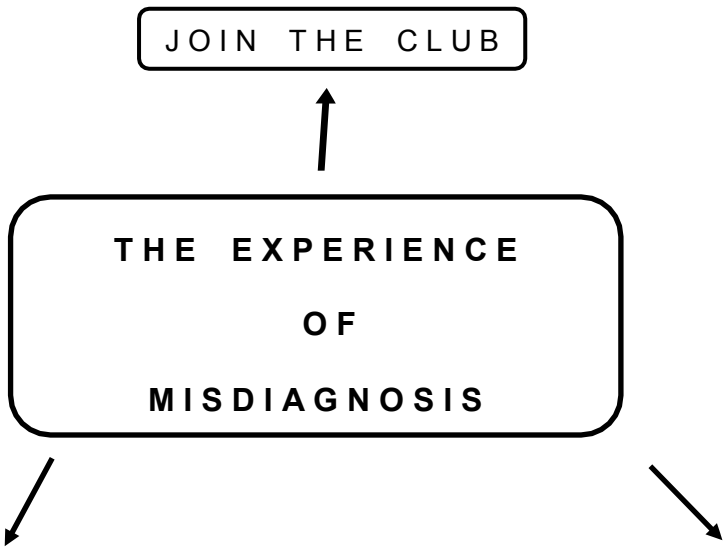
Ethical Considerations

According to The Code of Ethics and Conduct open discussion forums can be classed as public behaviour, although conducted in a technically private environment such as the home. It is also reasonable to argue there is likely no perception of privacy and research validity considerations to justify undisclosed observation, therefore use of research data without gaining valid consent can be justified (British Psychological Society, 2017). Anonymity and confidentiality were paramount throughout the study, although many of the participants posted on the forums using an alias to make them anonymous, the participant’s data was further anonymised by changing the individual user aliases or names to another pseudo name to protect their identity (British Psychological Society, 2017). As an additional safeguard the names of the websites were not disclosed. These precautions were of further importance as the right

to withdraw was not applicable to the current study due to the participant's anonymity.

Chapter Three: Results

The themes identified from the thematic analysis were; 'The Toll of Misdiagnosis' which contained two subthemes; 'The Breaking Point' and 'The Chaos of Symptoms'. The second theme was 'Join the Club' and finally the theme 'Double Edged Sword of Diagnosis' was identified which included the following subthemes; 'Relief' and 'Life Sentence'. Each of these themes and subthemes were discussed below in depth and supported by illustrative quotes from the data. Further, these themes and subthemes were visually displayed in a thematic map which can be seen below in Figure 1.



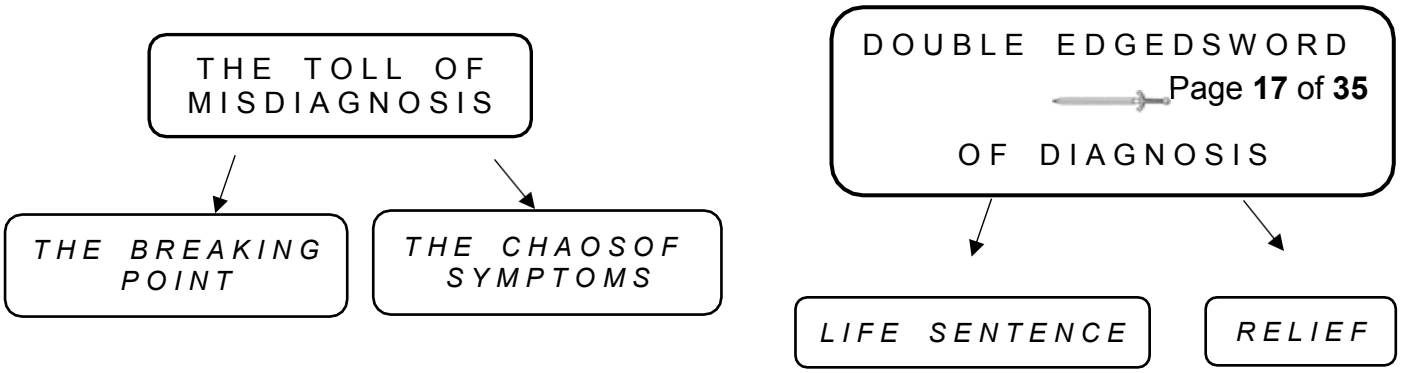


Figure 1. A thematic map displaying the themes and subthemes.

Theme One: The Toll of Misdiagnosis

'The Toll of Misdiagnosis' recognised that misdiagnosis impacted two key areas of participant's lives. The subtheme 'The Breaking Point' represented how misdiagnosis impacted participant's mental wellbeing. Whereas, 'The Chaos of Symptoms' acknowledged the negative impact to participant's general livelihood, impairing their ability to maintain stability in important areas of their life such as; relationships, employment and finances.

The Breaking Point

Misdiagnosis is much more than a case of an incorrect name. For the majority of participants, it referred to being prescribed incorrect medication. "The Breaking Point" attempted to demonstrate how catastrophic the impact of incorrect medication was on participant's mental health and wellbeing.

"I have had difficulty all my life but was misdiagnosed many times over the years. Finally last November I went screaming to my new gp doctor in desperation because nothing ever worked and I felt like I was losing my mind." – Casey. Page number: 6. Line number: 2-5.

"After years of being misdiagnosed as depressed, I finally has an episode large enough for my doctor to send me to a psychiatrist. Diagnosed BP2."– Herbert. Page number: 32. Line number: 1-2.

"Took me two suicide attempts until I was correctly diagnosed" Autumn. Page number: 37. Line number: 1.

The incorrect medication forced many participants to become victim to their disorder, having their lives dictated by unmanaged and overwhelming symptoms. Over time these relentless symptoms inflicted hopelessness in the participant's battle for mental health stability, often driving them to exhaustion or a sense of desperation which resulted in severe consequences such as breakdowns and attempted suicide. Unfortunately, for many participants it was only when these drastic actions resulted in hospitalisation that they finally received a correct diagnosis and gained access to appropriate treatment.

The Chaos of Symptoms

The subtheme highlighted how misdiagnosis led to severe consequences for participants, significantly impacting on important areas of their lives such as: maintaining healthy relationships, finances, careers and education. Many participants described how poor decisions in the past had impaired their future prospects and inflicted anxiety or guilt. Harry's quote provides evidence for this as he struggled to understand and accept his past behaviours.

"I just thought I was terrible because of all the destruction left in my wake. Why did I quit that job? Why would I drink so much? Why was I often so depressed and other times fine and other times really intense?" – Harry. Page number: 24. Line number: 3-5

Participants discussed how the instability of symptoms have caused struggles throughout their lives. Elijah described how this instability impacted his life for almost a decade which significantly impaired his journey to independence as a young adult.

"I can relate. I've been in and out of schools/jobs/home since highschool. I'm 24 now and just this month I ended up in hospital after a failed suicide attempt and I got diagnosed with BP2." – Elijah. Page number: 19. Line: 1-3

The treatment for BP- II disorder is first and foremost medication and the current subtheme highlighted how vital the correct medication is. Untreated BP- II disorder often causes symptoms to become out of control, causing destruction and dictating instability throughout participant's lives.

Theme Two: Join the Club

'Join the Club' recognised how common the issue of misdiagnosis is within BP- II disorder. It also highlighted the sense of community that was evident throughout the forums, allowing participants to make connections with others, while providing empathy, understanding and support.

Join us in the "Bipolars originally misdiagnosed as depression club!" – Shiloh. Page number: 22. Line number: 1.

"We need people who can meet us where we are at, people who aren't close personal people, people who are in the trenches and still struggling to manage that bipolar beast. We are working really hard and we know what you are talking about because we are there with you." – Olivia. Page number: 6. Line number: 2-5.

"First off, I'm sorry you had to go through the experience of a suicide attempt. I have never done so myself but I have gotten close (i.e. literally finger on the trigger) and I know how phenomenally awful that feels. I'm glad you made the decision to seek help at a hospital. I consider that a very brave thing to do. My experience may be somewhat similar to yours. My depressive episodes started at age 10 and I was misdiagnosed with major depressive disorder at age 15." – Alfie. Page number: 21. Line number: 1-6.

The forums offered an opportunity for individuals to be heard and perhaps more importantly, understood. Shared personal stories of desperation and suicide attempts were met by familiar understanding rather than shock. It became impossible to ignore how prolific misdiagnosis is within BP- II disorder and how many participants had tragically faced similar situations. Additionally, the theme addressed how vital online support groups were for participants to receive empathy, support and understanding that may not have otherwise been available to them.

Theme Three: Double Edged Sword of Diagnosis

The 'Double Edged Sword of Diagnosis' acknowledged the participants diverse reactions to finally obtaining a correct diagnosis of BP-II disorder. The subtheme 'Relief' described how many participants found comfort in finally being able to understand their symptoms, make sense of their past actions and vitally; gain access to the correct treatment to begin their journey to stability both mentally and throughout their lives. Whereas, the subtheme 'Life Sentence' discussed the struggle that many faced in accepting their new diagnosis. A number of participants reported that the diagnosis was overwhelming due to its permanent nature and confessed worries about the stigma attached to bipolar disorder.

Relief

The name 'Relief' was chosen for the current subtheme as it was the expression most frequently used by participants in describing their emotions in their reactions to gaining a correct diagnosis, therefore, it only felt appropriate to use the same phrase when naming the subtheme. Participants described significant improvements in their lives such as finally being able to achieve and maintain stability after gaining access to the correct treatment. This is suggested in a quote from Casey who described that diagnosis and correct treatment were a relief which helped to introduce calm and stability into her previously turbulent life.

"I won't go into the roller coaster of my life and many disasters, but

diagnosis and medication have been a relief. It took a little while to adjust to the meds but I am so much better than I have ever been." Casey. Page number: 4. Line number: 3-5.

Many participants such as Greyson and Arthur suggested that the diagnosis allowed them to make sense of their past behaviour which also helped ease negative feelings of guilt and shame.

"When I was diagnosed it was such a relief; suddenly the last 15 years made sense" Arthur. Page number: 27. Line number: 3-4.

"It was such a relief for me to finally have an explanation for the roller coaster that was my life and to get access to meds that actually help regulate my mood" Greyson. Page number: 23. Line number: 2-4.

The correct diagnosis also offered individuals a tangible language that they could use with their family and close friends, which was beneficial in promoting better understanding and improving relationships. Additionally, 'Relief' demonstrated the hardship of misdiagnosis as there would be no relief if misdiagnosis was absent of struggle.

Life Sentence

'Life Sentence' revealed that obtaining the correct diagnosis of BP-II disorder does not signal the end of struggle for some participants.

"I'm BP2 and couldn't accept my diagnosis 7 years ago. I was 52 and felt like my brain was broken. To be honest I still feel that way. Accepting the diagnosis was just impossible for me for a long time." Raine. Page number: 11. Line number: 1-3.

The subtheme attempted to encapsulate the struggles some participants faced in accepting their diagnosis. Although many participants had spent years or even decades searching for an answer to explain their mental health struggles, the diagnosis of BP-II disorder appeared too overwhelming for many as it felt much more permanent and stigmatizing than a diagnosis of depression. Many participants such as Naima described feeling trapped, cheated into an unjust life sentence or struggled to contemplate their future living with BP- II disorder.

"I'm only 20, and I'm in this constant state of hopelessness, even on my good days. I'm so tired of not being in control of myself, and I don't know how I can handle this for the next 60/70 years of my life.

Does it ever get easier to deal with? I don't want to feel like I'm trapped in my own mind for the rest of my life. What can I do?" Naima. Page number: 3. Line number: 4-8.

Overall, the themes and subthemes acknowledged and represented significant and common issues that were discussed by participants in their experiences of misdiagnosis within BP- II disorder. The themes demonstrated how prolific, destructive and worryingly common misdiagnosis is. Furthermore, it was highlighted that obtaining a correct diagnosis allows many participants to achieve stability both mentally and throughout their lives. Although, it was also suggested that the struggle does not end for some individuals once they have obtained a correct diagnosis.

Chapter Four: Discussion

The current study explored the experience of misdiagnosis within BP-II disorder. Previous research had proposed that misdiagnosis significantly increased suicide risk and negatively impacted employment, finances, substance abuse and social functioning (Matza, Rajagopalan, Thompson & de Lissovoy, 2005; McCombs et al., 2007 & McCraw, Parker, Graham, Synnott & Mitchell, 2014). These findings originated from quantitative research which failed to portray the individual voices and experience of misdiagnosis. Therefore, the current study aimed to demonstrate the experience of misdiagnosis within BP-II disorder through a thematic analysis of forums from online bipolar support groups. The analysis identified themes within the data that both supported and extended on previous research. Revealing that the inappropriate treatment from misdiagnosis inflicted an instability both mentally and throughout the participant's lives which increased feelings of hopelessness and risk of suicide. Not only did these findings reveal the devastating consequences of misdiagnosis but also determined that the current diagnostic process for BP- II disorder is inadequate and leaves too many individuals misdiagnosed for far too long. The present study further acknowledged that there was a lack of offline support for those who have been misdiagnosed or have eventually receive a diagnosis of BP- II disorder. While some participants found relief at finally obtaining an answer, many struggled to adjust to the new diagnosis and were left trapped with persistent feelings of confusion, upset and hopelessness with only online support groups for help. These findings will now be discussed in relation to their

themes, previous research, considerations and implications for future research.

The current study exposed that misdiagnosis was not just a case of an incorrect diagnosis but ultimately a referral for incorrect treatment. 'The Toll of Misdiagnosis' represented the impact of misdiagnosis's subsequent ineffective treatment in two subthemes, 'The Breaking Point' and 'The Chaos of Symptoms'. 'The Breaking Point' portrayed the impact of misdiagnosis on participant's mental health. Participants described feelings of intense emotional distress, hopelessness and desperation which gradually built up to crisis points such as mental break downs and suicide attempts. These findings were consistent with previous research which suggested that misdiagnosis decreased patient's wellbeing and significantly increased the risk of suicidal ideation, attempts and consequently hospitalisation (McCraw, Parker, Graham, Synnott & Mitchell, 2014; Undurraga, Baldessarini, Valenti, Pacchiarotti, & Vieta, 2012). Many expressed that hospitalisation granted them access to otherwise unavailable support services such as psychiatrists. Therefore, some participants revealed that they were grateful for reaching these crisis points as it was their only escape from the limbo of misdiagnosis and a hopeful route to stability. Yet, others felt their distress went further unnoticed or mismanaged by mental health professionals. For those participants, it had taken multiple suicide attempts to be given the appropriate support, a correct diagnosis and perhaps most importantly; access to the correct treatment. This supported the proposal that misdiagnosis significantly contributes to an economic burden (Gupta & Guest, 2002; Kleine-Budde et al., 2014; Parker, 2012). Several participants voiced experiences of countless doctor's appointments, sick days from work and substantial use of psychiatric and hospital services that in some cases spanned over decades. Arguably, many of these experiences and expenses could have been avoided if the participants had been correctly diagnosed and received the appropriate treatment. Another consequence of mistreatment was identified in 'The Chaos of Symptoms'. This subtheme described how misdiagnosis left participants with untreated symptoms of overwhelming depression and chaotic hypomania which inflicted instability throughout significant areas of their lives. These findings were consistent with previous literature which suggested that misdiagnosis impacted on personal finances and employment (McCraw, Parker, Graham, Synnott & Mitchell, 2014). However, the current study also revealed that the inability to maintain stability caused participants feelings of great shame, guilt, anxiety and created impairments or fear for their future prospects. Further, many felt so overwhelmed that they were then forced to leave education or employment and move back home with their parents to try and regain stability.

These devastating consequences of misdiagnosis were expressed by every participant to some degree. Their comparable distress was

portrayed in the theme ‘Join the club’ which demonstrated and supported the high prevalence rates of misdiagnosis found within BP-II disorder (Angst, 2013; Awenat et al., 2013; Hirschfeld, Lewid & Vornik, 2003 & Miller, Johnson & Eisner, 2009). Further, many participants discussed being misdiagnosed specifically with a depressive disorder which also supported the suggestion that mistaken depression is a significant issue within misdiagnosis of BP-II disorder (Angst, 2017; Kuppili, Yadav & Pattanayak, 2017; Miller, Johnson & Eisner, 2009). Additionally, these findings corroborate with the proposed inadequacy of the current diagnostic process and the need for immediate improvement (Angst, 2013; Awenat et al., 2013; National Institute of Mental Health, 2018). One recommendation to improve diagnostic success is the application of hypomanic screening, as the recognition of hypomania is key to separating BP-II disorder from depression (Angst, 2013). Hypomanic screening is also simple to administrator, time efficient and cost effective making it a realistic implementation to the current diagnostic process (Benazzi & Akiskal, 2003; Wong, 2011). Although longer term solutions to misdiagnosis must question as to whether the issue of misdiagnosis lies within the diagnostic process for BP-II disorder specifically or the current diagnostic approach as a whole. The British Psychological Society's proposal to move away from the diagnostic systems such as the DSM-5 must be considered; as reliance on the disease model is arguably flawed and outdated (Awenat et al., 2013). Although, the current diagnostic process is debatably ineffective and leaves many to be misdiagnosed, the online forums provided the participants with an opportunity to share their experiences and express their frustrations while gaining support, knowledge and understanding. ‘Join the Club’ acknowledged the sense of community evident throughout the online support groups. These findings support previous research that demonstrated participation in online support groups can provide important coping mechanisms such as friendships and emotional support (Bauer, Bauer, Spiessl & Kagerbauer, 2013). The present study also identified that offline support such as education and support groups were not currently available for the of majority participants, which led them to rely on the online support groups for information and guidance. Yet, it was also highlighted that online support groups offered a unique opportunity for those who felt they have been misdiagnosed but do not feel comfortable engaging in a face to face bipolar support group without an official diagnosis.

However, participant’s responses to finally obtaining a diagnosis of BP- II disorder were complex, contrasting and fluid which was represented in the theme ‘Double Edged Sword of Diagnosis’. These findings were consistent with a small but growing research area which proposes that participants have varying degrees of acceptance to their BP- II diagnosis (Fisher, Manicavasagar, Sharpe, Laidsaar-Powell & Juraskova, 2017). The theme represented the dichotomy of

these responses within the two subthemes of 'Relief' and 'Life Sentence'. 'Relief' embodied the relief that participants experienced once correctly diagnosed with BP-II disorder. Many described that the diagnosis allowed them to access correct treatment, a chance for stability and ultimately; hope for the future. Therefore, supporting previous research that suggested a diagnosis can inspire optimism (Kokanovic, Bendelow & Philip, 2013) and also confirmed the importance of medication for the treatment for BP-II disorder (Kendall, Morriss, Mayo-Wilson & Marcus, 2014).
Additionally, the length of misdiagnosis was frequently discussed throughout the forums and was fairly consistent with previous research that suggested it can vary between five and fifteen years (Singh & Rajput, 2006; Tondo, Visioli, Preti, & Baldessarini, 2014; Mosolov et al, 2014). However, the current study also identified participants who had experienced much longer periods of misdiagnosis of up to forty years. Prolonged misdiagnosis has been associated with impaired recovery and future prognosis which has potentially severe implications for these individuals such as impaired recovery and response to treatment (Kapczinski et al., 2014; Lish et al., 1994; Mosolov et al, 2014; Undurraga, Baldessarini, Valenti, Pacchiarotti, & Vieta, 2012). Although, participants in the current study who experienced shorter lengths of misdiagnosis also expressed considerable distress which demonstrated that any length of misdiagnosis is unacceptable and has potentially damaging consequences.

Nonetheless, a correct diagnosis did not signal the end of the struggle for some participants and could even create new difficulties. This was represented in the subtheme 'Life Sentence' as many participants expressed that the diagnosis of BP-II disorder felt much more permanent, stigmatising and overwhelming in comparison to remaining undiagnosed or misdiagnosed. These findings supported previous research that claimed a diagnosis can burden patients (Peterson and Madsen, 2017) and challenge their identity (Kokanovic, Bendelow & Philip, 2013). This emphasises the need for psychoeducation to those who have been recently diagnosed with BP-II disorder, particularly after being misdiagnosed in order to tackle these issues and improve the adjustment period (Proudfoot et al., 2018).

Overall, the themes reflected the impact and experience of misdiagnosis through a thematic analysis of online forums which allowed for rich data collection. Previous research established that online support groups offer an anonymous platform where users can freely express themselves without fear of judgement (Frye & Dornisch, 2010; Suler, 2013). These potential benefits could have provided the current study with richer data to deeper explore the impact of misdiagnosis. However, Internet mediated data collection

could have also faced the potential disadvantages of the researcher misinterpreting participant's posts due to lack of paralinguistic features or misunderstanding of the context (Hewson, 2014; Mann and Stewart, 2002). Moreover, the current form of data collection left no opportunity for the researcher to verify their interpretation with the participants (Giles, 2016). Yet, it could also be argued that the asynchronous nature of online forums gave participants the opportunity to consider how they presented their experiences and even an option to edit them which could have potentially reduced misinterpretation between the participant and the researcher (Chen & Chiu, 2018). Another possible limitation within the current study was that the thematic analysis was only performed by one researcher which could mean that aspects of the data were missed. However, Braun and Clarke's (2006) '15-point checklist of criteria for good thematic analysis' was utilised during the process of analysis which could have provided support against these potential pitfalls. Although, issues such as potential misinterpretation or missed points could also be addressed in future research by using another form of data collection such as a face to face semi structured interview. This method of data collection would give the researcher an opportunity for verification of the participant's views which would ensure that the analysis correctly reflected their experiences. A semi structured interview would also allow the researcher opportunities to ask the participants additional questions or to elaborate on specific points to further explore the experience of misdiagnosis. Lastly, the social cues from face to face interviewing could potentially enhance the researchers understanding and result in a higher quality analysis (Opdenakker, 2006). Future research could also explore the individual response to BP-II diagnosis as the present study has found that this can vary drastically and could add to an emerging field of research investigating response to BP-II diagnosis and its implication for treatment (Fisher, Manicavasagar, Sharpe, Laidsaar-Powell & Juraskova, 2017).

In conclusion, the present research demonstrated that misdiagnosis resulted in devastating consequences for the participants. Revealing that ultimately misdiagnosis referred to mistreatment which inflicted instability throughout many areas of the participant's lives and increased overwhelming symptoms, suicidal ideation and attempts. The present study also exposed the unacceptable prevalence and longevity of misdiagnosis within BP- II disorder and thus suggested that the capability of the current diagnostic approach needs to be questioned. Arguably, the biggest challenge in diagnosing BP- II disorder is the recognition of hypomanic symptoms. Therefore, the current study supported the implementation of hypomanic screening to separate BP- II disorder from its most commonly mistaken disorder of depression. Improvements in diagnosis would not only benefit many individual's mental wellbeing and provide access to essential treatment but could also reduce the economic burden of

misdiagnosis. Furthermore, the present study also discovered that there was a lack of support for those who have been diagnosed with BP- II disorder even after previous misdiagnosis, which left many to turn to online support groups for guidance and support. Therefore, the present study also highlighted the necessity for services such as psychoeducation to improve the adjustment period to the diagnosis of BP- II disorder.

Reflexive analysis

Reflexivity is a process that allows the researcher to recognise how their own values, opinions and experiences may have influenced their research (Nightingale and Cromby, 1999). The process is important as it permits the researcher to demonstrate an awareness of their own subjectivity such as motivations or assumptions and how they impact on the research and the analysis (Yardley, 2000). The motivation for and throughout the research process was to bring awareness to the impact of misdiagnosis within BP-II disorder. The current research question was influenced by my own experiences of witnessing a family member suffer from long term misdiagnosis and subsequent incorrect treatment. These experiences may have enhanced my understanding of the participant's experiences and allowed me to reflect their experiences to a higher standard (Bonner and Tolhurst, 2002). In spite of these potential benefits, it must also be considered that researching an area that is very familiar or personal may interfere with the objectivity, reflexivity and authenticity of the research (Kanuha, 2000). However, Rose (1985) suggested that there is no true neutrality, only greater or less awareness of one's biases. Moreover, the qualitative approach acknowledges researcher subjectivity and further suggests that it can enhance the research process instead of hinder it (Etherington, 2004).
Previous research had only considered this topic using quantitative methods and from my own experiences and research I felt strongly that they did not capture the full impact of misdiagnosis. This influenced me to utilise qualitative methods for the current research, in particular a thematic analysis to reflect the experience of misdiagnosis by identifying themes from the data. Although, it could be claimed that my experiences and motivations could have provided me with a certain level of bias, I feel that they allowed me to engage with the data on a deeper level, notice finer details and enhance the quality of the analysis (Dwyer & Buckle, 2009). Much time and effort was spent on each phase of the six-phase thematic analysis as I was determined to ensure that the analysis truly reflected the participant's experiences of misdiagnosis (Braun and Clark, 2006).

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Word Count Statement

Introduction	3,183
Method	1,403
Results	1,772
Discussion	2,390
Total	8,752

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Natasha Smith

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