

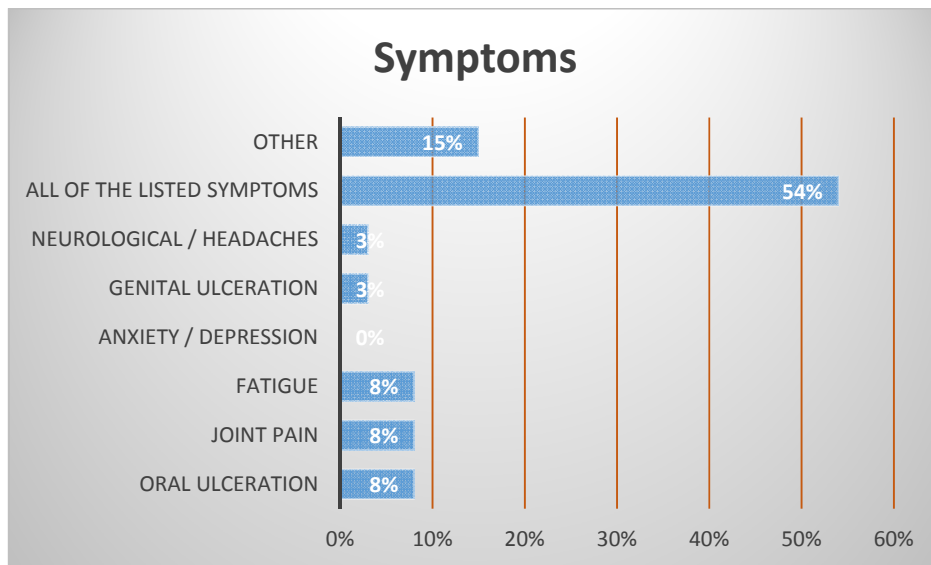
Behcet's Disease.

Behcet's disease (BD) also known as Behcet's syndrome is a rare and chronic multi-organ disorder. This is caused by a malfunction within the immune system; causing the immune system to become over active. This over active behaviour causes inflammation within the blood vessels (BSS, 2013). The most common symptoms of this disease are oral and genital ulcerations; accompanied by, gastrointestinal involvement, skin irritation, inflammation of the joints, causing arthritis, eye inflammation, chronic fatigue, migraine defined headaches (BSS, 2013). There is also the risk of neurological involvement, lesions or ulceration on the brain or inflammation of the central nervous system, which will complicate matters further. It is understood that stress can be a contributing factor when a patient endures an outbreak of these symptoms.

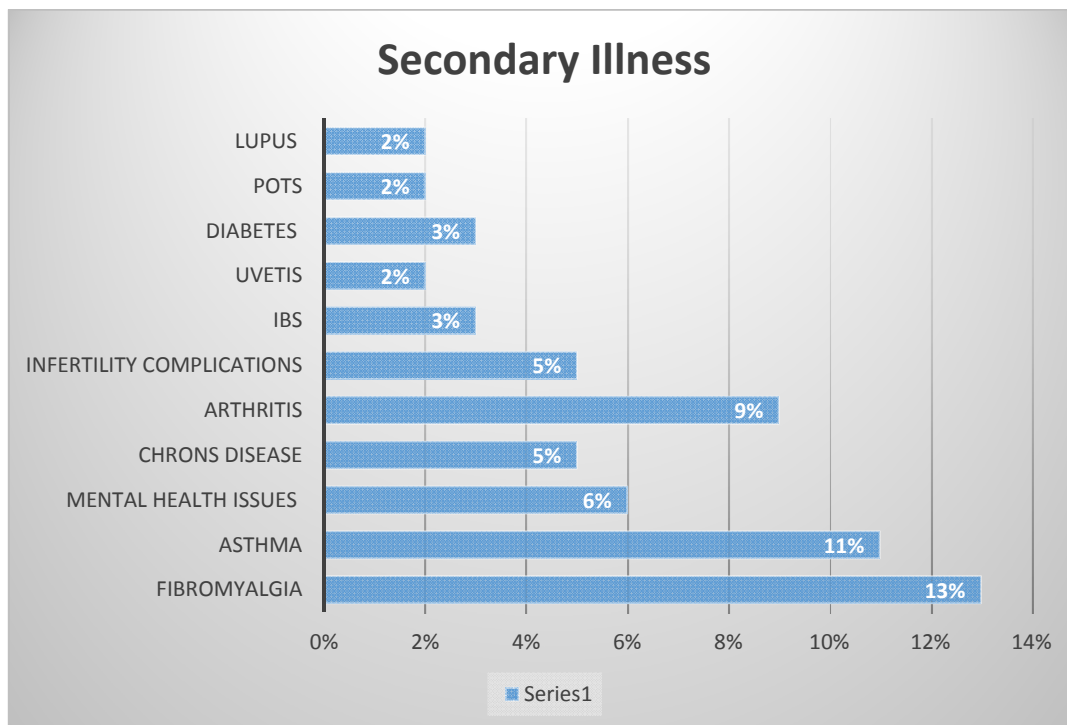
BD is rare within the UK, it is estimated that around 1 in every 100,000, that is 1000 people that have been diagnosed, arguably this figure maybe higher with individuals who are still awaiting a diagnosis (BSS, 2013). Behcet's is more common in those of Middle Eastern and Mediterranean descent. According to Zeis (2006) statistics show that that diagnosing BD patients has remained consistent; the UK has approximately two thousand cases, compared to Japan thirteen thousand cases, USA fourteen thousand cases and the Middle East with the highest rate of BD cases at twenty -seven thousand people diagnosed. As the statistics show, those with a Mediterranean or Middle Eastern background are more likely to develop BD, tests show a connection between BD and the protein HLA-B51, which is located upon the red blood cells (Vasculitis UK, 2015). Although this is not a conclusive indicator for diagnosing BD. The HLA-B51 protein is less common in those from western countries, such as the UK and the USA.

In terms of receiving a correct diagnosis for BD within the UK, there is no definitive test specifically for Behcet's. This then becomes a process of elimination; this is due to the similarities of other autoimmune disorders such as Crohns Disease, Lupus, Ulcerative Colitis or Lyme Disease (Zeis, 2006, p69) According to the American Behcet's Disease Association (n.d) the International study group diagnostics guidelines the criteria for diagnosing BD is oral ulcerations of any size or number must occur three or more times in a twelve-month period. For many BD sufferers many

of the symptoms experienced along with the oral ulceration is indicated in the pie chart below, with 55% of participants experiencing all of the symptoms listed. Although in the chart anxiety and depression did not receive a separate selection however this was included within the 15% other category: where participants were able to add their own comments.

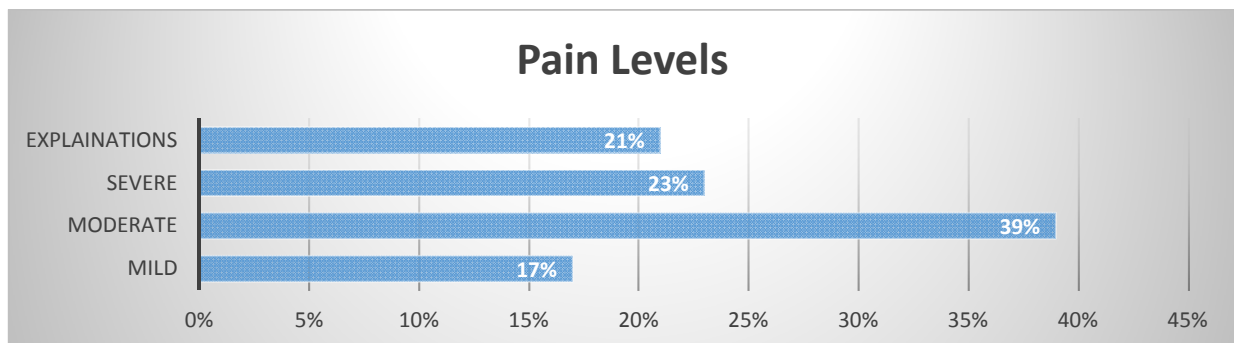


These symptoms must also be accompanied by a further four symptoms of eye problems including loss of sight, genital ulcerations, skin lesions and a positive pathergy test. These symptoms are extended when using the practical clinical guidelines, which indicate the following symptoms; Arthritis, gastrointestinal complaints, deep vein thrombosis, cardiovascular complaints, chronic fatigue and personality changes or psychoses, history of family members with the condition (BSS, 2013). For many individuals BD is often accompanied by secondary illnesses such as Fibromyalgia. the chart below indicates the illnesses that are seen as secondary in comparison to the BD itself.

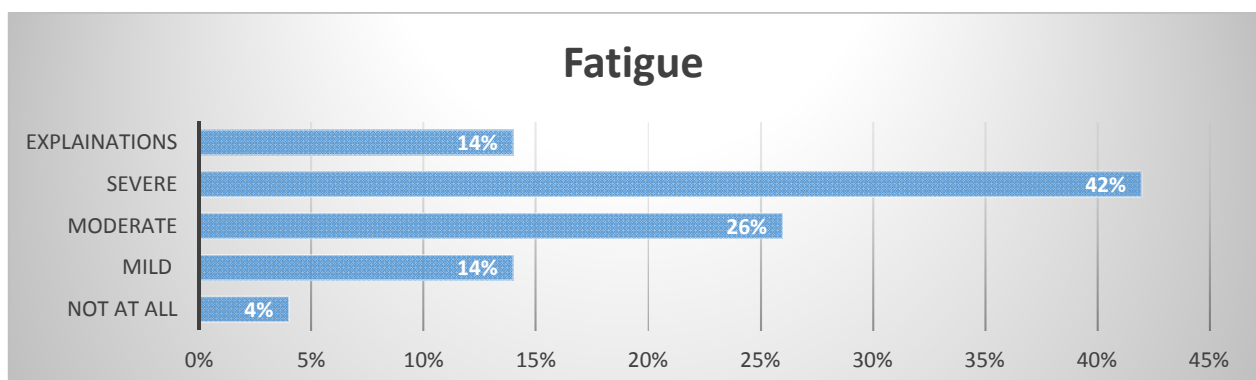


The neurological involvement or the involvement of the central nervous system affects between five and fifty per cent of those with BD (Dutra et al, 2013). The main characteristic is a headache. This is usually a tension type headache, but is often accompanied with depression and psychotic episodes (Zeis, 2006, p125). These episodes can range in severity. However, in some cases a MRI or CT scan can show lesions on the brain that contributes to the condition.

With so many different symptoms to contend with; pain on a daily basis is to be expected. 39% of participants indicated their pain levels are at moderate level, with the help of medication. With a further 23% indicating that the pain is more severe. Participants also commented that medication includes the use of stronger medications such as Tramadol and Oramorph in order to control pain. Pain will also have an impact upon the mood of the individual. In this case 39% of participants found pain had a moderate affect upon their moods, while a further 21% found that the pain levels had a severe impact upon their moods ranging from irritability, depression and shortness of temper.



In addition to the pain, another contributing factor is fatigue. For any BD sufferers, fatigue can impact upon daily routines. With many finding that they require frequent naps or for the more severe cases needing to sleep for long periods at a time, for some it is that they find it impossible to make it out of bed. The impact fatigue has upon the mood is similar to pain with 37% finding their mood was moderately affected and 26% had a more severe impact upon mood, again depression, irritability and shortness of temper being the most common reactions.



With the unpredictability of this illness, the quality of life led by individuals can be somewhat diminished (Koutanji et al, 2003). According to the results over a two-week period 45% of participants found that BD impacted upon their ability to carry out normal day to day routines 18% of participants explained that in some instances the effect of BD is severe enough that they are unable to fulfil the simplest of duties; including being able to meet with family and friends becomes increasingly difficult, many participants find they are unsuccessful in keeping and maintaining social engagements. Many find that family and friends do not understand the impact of living with such an illness, which for many may result in the loss of friendships and strained

relationships within the family cohort. In situations where there is little contact with family and friends, there is a risk of the individual becoming socially isolated. According to Koutantji, et al (2003). This can be detrimental if they become socially isolated for long periods of time, increasing symptoms of depression and anxiety.

Psychological Impact of BD.

The psychological aspect of this condition could be the result of lesions on the brain. These lesions can develop at any time, however they could be more likely to appear within the first eight years from the point of neurological involvement (Zeis, 2006). Yamada et al (1978, as cited by Zeis, 2006, p19) there are different psychological stages of development. These changes begin with a change in personality. This may begin with carelessness, rudeness, depressive symptoms or euphoria. Although some patients may only experience infrequent bouts of psychological issues; which may include forced emotions, hallucinations confusion and sleep disorders.

Many of the studies are focused upon the mood disorders such as depression. According to Uguz et al (2007) patients with BD, have a higher rate of depression and anxiety, which impacts upon their quality of life. Depression and anxiety rates have been to be at the highest of eighty-six per cent, after a diagnosis is given. However, depression has also been linked to steroid usage to treat the condition. Arguably depression and anxiety can be caused by the change in circumstances after receiving a diagnosis. For many this change brings isolation, social exclusion and the loss of a relationship or even employment, which may be due to the unpredictability of the illness, but also due to the lack of knowledge and understanding (BSS, 2013).

There have been previous studies into links between Behcet's disease, low mood and quality of life. This has highlighted that serious illness has a significant impact upon a patient's psychological distress, and for those in an active state of illness their mental function is affected (Koutantji, M. et al 2003).

According to Angermeyer et al (2003, as cited by Green et al, 2005) social isolation may also be the result of stigma that accompanies illnesses and disabilities to which society does not accept or fully understand.

According to Goffman (1963) there are three types of stigma. Firstly, variations in personal trait, invisible imperfections such as mental health issues, invisible illness would also fall under this category. Secondly Internal and external imperfections, this includes visible scarring, physical disability and social disability. Thirdly Tribal stigma that is related to race and religion.

Stigmatization occurs when an individual is considered different or unusual to the majority of society. Unfortunately, those who have a condition that may be to some degree invisible, the stigma comes in the form of being labelled as lazy, work shy, or benefit scroungers. Society does not appear to understand that not all illnesses or disabilities are visible. By stigmatizing an individual, society is placing the individual into a sub-category of society; therefore, treating the individual as a second class citizen (Reeve & Donna, n.d, p86). Green et al (2005) stigma contributes to depression and self-perceptions of negativity. It is undoubtable that all the negative influences surrounding BD, stigma and social isolation will have a profound effect upon the individual and their abilities to succeed within society (Cahill & Eggleston, 1994, as cited by Green et al, 2005).

Many sufferers of BD, find it difficult to remain successful within education and employment. With 31% participants in full time employment, 19% in part time employment, another 31% added that they are no longer able to work and had been classified as disabled, or retired on medical grounds (table 4). As with any illness absence from work is inevitable, however the durations may vary. The results indicate that 20 % of participants had missed between 1-5 days' absence due to BD. However, 42% of participants added that they are now regarded as disabled and unable to work.

Education and Chronic Illness.

For young adults with chronic illness, education can be difficult. According to Shaw, Glaser, Stern, Sferdenschki and McCabe, (2010, p13) absenteeism is the most common reason for academic failure. Despite BD affecting predominately male, chronic illness affects more girls in terms of academic absence. According to Shiu (2001) those with chronic illness are 50% more likely to be absent from school or college. Arguably absenteeism is not the only contributing factor in academic failure. Vila et al (2003, as cited in Shaw et al, 2010, p14) states that for many children that suffer with a chronic illness reduced levels of motivation, lead to the refusal of attending school. Although it could be argued that this lack of motivation and refusal to attend school comes from cognitive impairments, stress and anxiety of the illness itself (Shaw et al, 2010, p13). This will also impact upon the social, emotional and psychological aspects that education supports, including the ability to make and maintain relationships within the academic environment (Shaw et al, 2010). For those who not taken seriously when reporting issues of ill health, can lead to behaviours resulting in what Merton (1948) terms self-fulfilling prophecy. Self-fulfilling prophecy occurs when there is a change in behaviour to suit the label that one has been given, therefore if there is disbelief in an individual's health condition, the individual may be labelled a hypochondriac. To be referred to as suffering with hypochondria, "a person who is abnormally anxious about their health" (Oxford Dictionary, 2015) is often seen in a negative way. The individual may then take on the persona of a hypochondriac, when in reality understanding of their illness is all that is required.

Employment, welfare and chronic illness

Employability whilst suffering with a rare and chronic illness can be difficult to maintain at what employers would class as an acceptable level of competence. According to Baanders (2012, as cited in Cecile et al, 2010) one of the most common consequences in chronic illness is the reduction in labour market participation. Arber (1987) found that those who were already employed were less likely to report a chronic illness than those were currently unemployed.

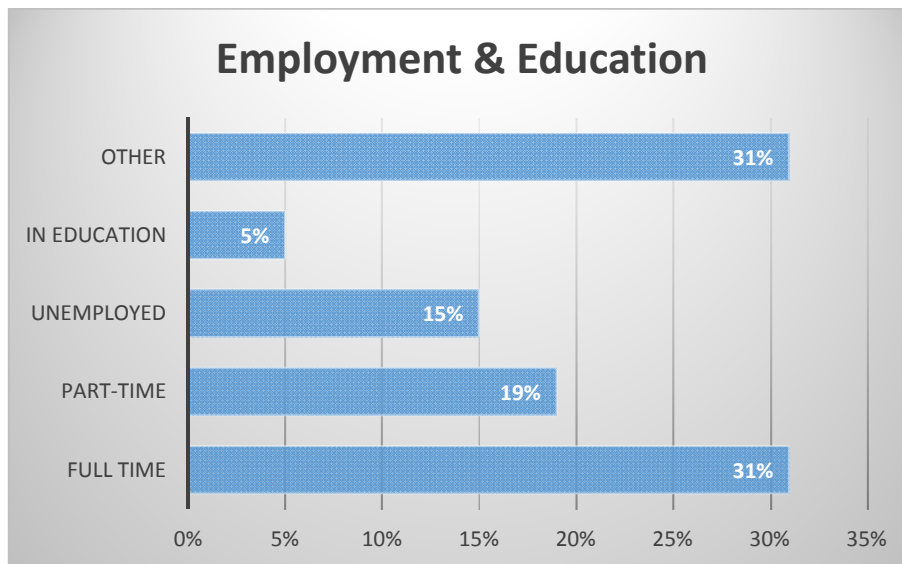
The most common indicator for an employer as to the health and employment capabilities of an individual is the amount sick leave one takes (Cecile, 2010). In this case, the employer is obligated under the Equality Act (2010) to ensure the individual can remain within their workplace. This includes making reasonable adjustments to their working environment if it is required, without the individual being victimised, or discriminated against.

Although employment is categorised as paid labour, Giddens (2012, p886) states employment includes voluntary work, in which positions of social importance are filled, but under acknowledged for improving upon an individual's quality of life. According to governmental statistics, in 2011 23% of disabled individuals participated in voluntary placements in comparison to 25% of able bodied individuals of a working age (Gov.org, 2014).

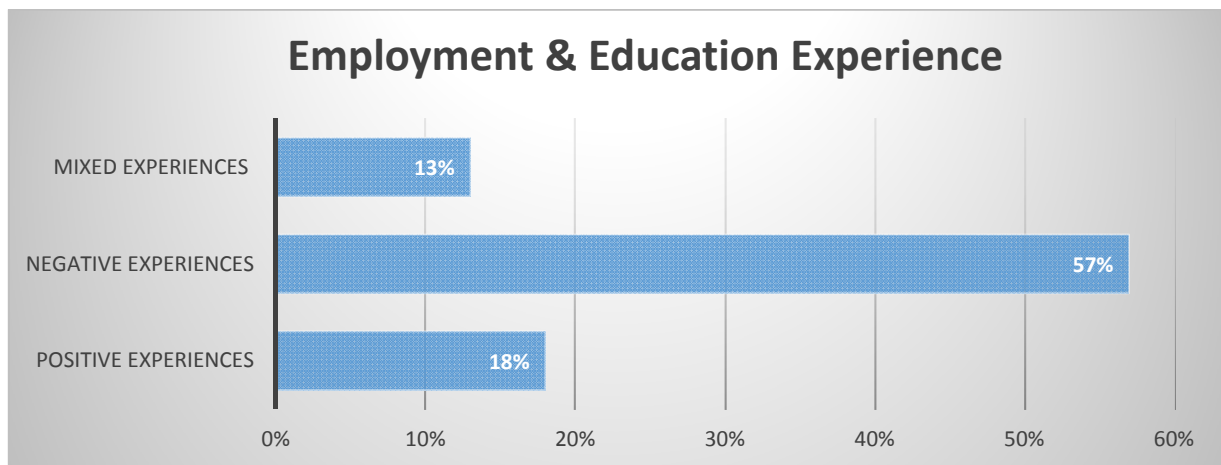
With the reduction in working hours, and the progression of chronic illnesses many families will resort to claiming welfare or state benefits. In 2011, 577,000 people within the UK, received benefits for having mobility related difficulties and 770,000 children under the age of sixteen being classed as having some form of disability. According to the DWP (2010) individuals with a disability will be unemployed long term, therefore becoming "economically inactive". More than half of those disabled claiming an incapacity benefit will remain unemployed over a five-year period. (DWP, 2010). However, for those with rare forms of chronic illnesses claiming welfare or state benefits such as Employment support allowance (ESA) can be a long and difficult process, often resulting in a lengthy appeal process. In order to claim any form of benefits, medical evidence is required with a medical assessment also possible to support the medical information given when applying, however this can be difficult with certain illnesses such as Behcet's disease, where the illness manifests in different ways. This can be difficult to obtain if the illness is not visible at the time of assessment.

The results indicate that in only 5% participants are currently in education, and a further 31% are still within full time employment, however many of those unemployed have indicated within the

31% of the other category this is due to being medically retired or unable to fulfil their role within the employment or educational sector.



As with any illness absence from work is inevitable, however the durations may vary. The results indicate that 20 % of participants had missed between 1-5 days' absence due to BD. However, 42% of participants added that they are now regarded as disabled and unable to work. Employers determine a person's employability prospects by assessing the amount of sick leave that is taken (Cecile, 2010). The more sick leave taken, the less likely an individual will be considered for employment or promotion, according to the Equality Act (2010) the employer has an obligation to ensure that appropriate measures are taken to support an employee where possible. Education can also be affected by chronic illness; therefore, the education institutions are also bound by the Equality Act (2010).



However, with more negative results, participants have found that there is little support offered by these institutions.

Medical Profession.

In order for an individual to maintain to their functioning role within society, it is vital to receive the correct treatment to control the symptoms, however this is not always a straight forward process. Once the referral has been made, waiting times for appointments on the NHS may vary. Although for those who are financially secure there is the option of using private health care. Private healthcare is perceived to be a shorter waiting time in comparison to the NHS (Goddard & Smith, 2001, p1152). Therefore, this could be dependent on societal status. According to Morris, Sutton and Gravelle (2005, p1264) inequality within the UK is based upon income, employment status, ethnicity and education; therefore, primary contact will be with their GP. However, they are less likely to follow up on secondary health care. Goddard and Smith (2001, p1154) adds that transport arrangements could also contribute to the lack of secondary care for some individuals.

Accessing the appropriate treatment may also depend on the geographical location. Some of the extensive treatment requires funding approval before treatment can begin, therefore the final

decision is that of the local health authority (Manning, Guardian, 2012). For some patients this could be the start of what is termed a postcode lottery. Depending on the geographical location, may depend on the available funding. (Manning, Guardian, 2012). For those with a serious but rare condition, having access to the correct drugs is of concern, according to the Guardian (2012), these drugs are less likely to be given if patients are living within England. A spokesman for the department of health commented within the article, that those with rare illnesses are not missing out on drug treatment that maybe vital to control such conditions (Guardian, 2012).

As there is no specific test for Behcet's Disease (BSS, 2013) it can be difficult to obtain the correct diagnosis. The responses received from the participants reflected the difficulties with this, however there were some positive responses.

"In the main excellent. Pre-diagnosis there was a lot of disbelief and disconnection between psychologists getting involved who wanted to label me as bipolar and the medics who understood was all Behcet's. I was sectioned wrongly on two occasions which was very distressing"

"Extremely poor. took 23 years to get a diagnosis, when it finally came they put me on so many medications it made me worse and damaged organs and bones leaving my life expectancy diminished"

"Really good once I was finally referred to specialist but took me 4 GP's and seven years to be referred"

"Reasonable. My journey with BD started 32 years ago and things were very different back then"

For the individuals of society who suffer chronic illnesses such as BD, Discrimination is evident within every area of society. According to the English federation of disability sport, 38% of people thought that disabled individuals are a burden upon society, with 27% of people acknowledging that discrimination comes from a lack of knowledge. With another 65% of individuals avoiding any form of contact with those classified as having a disability, as a result of not knowing how to interact around them. However only 7% of people class mental illness as disability, but this is only after being informed of the disability.

Unfortunately, 44% of BD sufferers have experienced some form of discrimination,

“It took months of fighting to get Student Finance to recognize it as an actual condition and to offer me support. They said it didn't impact everyday life and still can't spell it right.”

“At one work place I was told I would not have a permanent contract because my sick leave was too sporadic.”

In a way. Have been made fun of because of the mouth ulcers that manifest, not only inside, but outside my mouth.”

Despite legislations like the Equality Act (2010), which incorporates the Disability Act of 1995, many individuals still feel discrimination within the workplace is still apparent. In April 2000, Tony Blair set up the Disability Rights Commission, in order to end discrimination against those who have a disability (Barnes, 2000, p449). However, considering the magnitude of discrimination, Barnes (2000, p 449) argues that the Disability Rights Commission has been of little success.

For those who no longer work as a result of BD or the complications that come with it, the only way of supporting themselves financially is to apply for state benefits or welfare assistance. According to statistics given by the English federation of disability sport, around 577,000 people within the UK receive benefits in relation to mobility related issues. More than half of those disabled claiming an incapacity benefit will remain unemployed over a five-year period. (DWP, 2010).

With BD being a sporadic illness with no set pattern or guaranteed visibility; obtaining state benefits or welfare assistance can be a difficult process in some cases. Participants highlighted that applying for benefits is not an easy process, which could be related to the lack of understanding of BD,

“I tried twice to claim DLA and refused both times”

“Denied 3xs because it's an unknown disease”

“It took ten years to get DLA and had to go to tribunal but then was only given it for 3 years. Had to reapply all over again and was turned down so back to appeal then tribunal and was given it for 5 years then again reapply and turned down so same again where I was lucky to get a consultant that new about BD and was given it for life. Now just had to reapply for pip and they have not given me it so it starts all over again.”

Although other claims for more well-known illnesses have been successful, for others with more severe symptoms of BD, some of the claims have been successful.

Conclusion

Behcet's disease is a rare but chronic illness, with an estimated 2000 people diagnosed with the condition within the UK. BD is a multi-organ illness, therefore symptoms can affect a significant area of the body, and with the exception of oral ulceration the majority of symptoms are internal. Therefore, to some degree BD can also been seen as an invisible illness (Zeis, 2006). The invisible symptoms include arthritis type joint inflammation, which may display mobility issues, migraines, depression and anxiety.

The journey to receiving the correct medical care can be long and stressful experience. Not all of the medical profession are familiar with BD, which could result in the individual being treated as if there is nothing medically wrong, in which case may exacerbate mental health issues. Uguz (2007, p21) found that one fifth of BD patients suffer with major depression, with increased anxiety.

Living day to day with such conditions will greatly influence the quality of life one may lead. In the severe cases the quality of life becomes minimal, rendering the individual confined to the home or even bed bound.

With chronic illness comes discrimination, this may be related to the lack of knowledge and understanding of such a rare condition. This appears to also be the case within the medical profession. As a result of this the chances of receiving the correct treatment will be delayed, however this could also be dependent on funding and the geographical location of residence (Guardian, 2012. This may be detrimental to the health of the individual. If complications arise through the delay in treatment this could in some cases result in death, according to Zeis (2006, p16) the mortality rate is around 3-4 %, although Kural et al (2000, as cited by Zeis, 2006, p16) argues that this figure is closer to 6%, that is directly related to the complications of BD or Neuro-Behcet's, the involvement of the central nervous system.

It is clear from the information gathered in this study that further research is required into: Accessing the correct medication regardless of the geographical location an individual resides.

Ensuring that the medical profession regardless of position is aware of rare and chronic illnesses to ensure the correct treatment plan is obtained.

And finally raising awareness within society so that discrimination is reduced within every aspect of society.

A PSYCHOSOCIAL ANALYSIS OF LIVING WITH A RARE AND CHRONIC ILLNESS: BEHCET'S DISEASE.

Emma Hellwing

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