

The impact of multiple sclerosis nursing essay



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A chronic illness refers to a disease that lasts over a long period of time and consists of slow changes, in which the onset is gradual^{1, 2}. It is widely recognised that chronic illness comes with its associated stigma and therefore can significantly affect the lives of the patients and their family³. The aim of this report is to focus on the impact of MS on the patient volunteer and her family.

The Interview

Melanie (pseudonym of patient volunteer) was a 75 year old lady who suffers from MS. The interview took place in Melanie's home which enabled me and my colleague to observe the patients surroundings, such as the environment that they lived in and how it has been adapted solely to meet her needs. We came to the interview with pre-prepared questions to ask from the patient, including some contingency questions just in case the interview did not flow as planned. It was also decided that I would take the notes in the interview and my colleague would ask the questions. This way eye contact would be maintained and this would allow the conversation to flow.

Multiple Sclerosis (MS)

MS is a disorder which creates communication difficulties in nerve cells in the brain and spinal cord; in their ability to send action potentials along axons. MS is defined as the demyelination and scarring of the axons causing damage to the myelin sheaths around the axons as a result of an autoimmune response. This demyelination can potentially lead to a broad spectrum of signs and symptoms (e. g. muscle spasms, fatigue and optic neuritis etc)^{4, 5, 6}. The symptoms of MS usually appear in episodes and are

identified as relapses, which are often unpredictable¹. The onset of this disease is usually among young adults and is more common in females. This disease is prevalent between the ranges of 2-150 people per 100, 000⁷, and affects approximately 85, 000 people within the UK making it the commonest neurological disorder among young individuals in the UK⁸. However, the cause of MS remains unknown, but some theories include a combination of environmental, infectious or genetic factors as the underlying cause of MS^{1, 8, 9}.

Coping with the Diagnosis of MS

It is very common for denial, confusion and fear to be the immediate responses for people who have been diagnosed with a chronic illness¹⁰. Unlike other chronic illnesses, MS is a disease that isn't diagnosed immediately at birth therefore the burden of coping with several diagnostic tests, may generate anxiety in the patient and their family members. In some cases MS diagnosis can be difficult as a result of unclear test results which can further raise fear amongst patients⁸. Furthermore, Mechanics, 1968, defines illness behaviour as the evaluation and perception of symptoms that an individual experiences, and the action taken to counteract the experienced pain and discomfort^{1, 11}. Directly relating this to the volunteer, the action taken by her was to continuously go to the doctors in order to receive a diagnosis because she was adamant in the belief that something was wrong. On the contrary, many people within communities form part of, ' The Clinical Iceberg' which justifies why many health care practitioners are unaware of their patients' symptoms and conditions due to failure in patients visiting their doctors¹¹.

The diagnosis of MS can potentially impact aspects of individuals' life and their families. The unfamiliarity, lack of awareness and the seriousness of the illness presents a significant amount of burden upon the sufferer and other involved family members, which may set free feelings of anxiety, anger and fear^{3, 13, 14}. These feelings were mirrored in Melanie's husband once she was diagnosed. However, coming to terms with the illness was undergone with support and advice from consultants and other professionals.

To many patients and carers it is a relief knowing that their condition will not deteriorate. This is not the case with MS as it is a progressive disorder and coping with its deterioration is one of major aspects that patients have to overcome. Furthermore, aid in coping with a chronic illness can be found amongst support groups because it's an opportunity to meet people in similar, or worse situations and to learn from them and further allows patients to play an active role in their care^{15, 16}. Melanie found the West Yorkshire Therapy Centre helped her to cope with her condition by having a network of individuals to converse with and share feelings with. Despite there being benefits of support groups, some people prefer to remain absent from support groups in order prevent the feeling of the illness seem too real, and to not see people who are managing their illness better than them¹⁷.

Impact of MS on quality of life

The quality of life is determined by how the individual reacts to their diagnosis of the illness^{1, 11}. Individuals and that of their families life can be impacted by chronic illness as it is present for a lifetime^{1, 17}. The impact of MS can vary just as the severity of MS also varies. The individual and certain family members have to make adaptations to their lifestyle to accommodate

for continual appointments^{14, 17}. Having a chronic illness can have a negative impact on the independence and self-control and therefore may require reliance on others¹. The volunteer really depended on her husband and grandson for attending appointments and relied on her sister, who lived nearby for company when attending the appointments.

Social isolation and a change in lifestyle are two of the key problems that are likely to be experienced by chronic illness patients as outlined by Strauss 1984¹. As a duty of care, caregivers are also restricted socialisation due to the commitment for caring for the patient and purposely may avoid socialising in order to give quality care to the patient¹⁸. Social isolation was experienced by the volunteer due to attending appointments, which limits time and also due to her mobility, accessing many homes proved difficult, those of friends and family. This can adversely impact the daily activities and hobbies of the patient and in turn, the social time spent with family and friends.

One of the treatments that the volunteer undergoes is using the hyperbaric oxygen chamber, which has affected the quality of life of the volunteer. Melanie has found the treatment very time consuming, and therefore felt that it confined time for other activities. However, when being in the oxygen chamber, other people are also present at the same time, which combines socialisation with treatment.

Research has shown that caregivers health can also be in compromise due to increased responsibilities and exhaustion, which can potentially lead to depression¹⁸. Uncertainty within the chronic condition and future

implications concerning the sufferers and their family has been responsible for the greatest psychological stressor (Koocher 1984).

Stigmatisation

Goffman defined stigma as disqualifying an individual from full social acceptance. He further illustrated through several studies that the chronically ill are stigmatised due to them not fitting in with society and the widely accepted social norm^{1, 16, 19}. The physical disabilities of MS sufferers often cause them to be stigmatised making them perceived to be inferior to others¹⁶. Callahan and Jennings findings show that chronic illness and disability are frequently bounded with stigma, mainly due to a lack of education, unfamiliarity of the disease and misconception. Melanie found that after her diagnosis, and when her symptoms were more apparent, especially when walking, she experienced that her neighbours had become more distant, but in the contrary her family and friends became closer and proved very supportive.

Research has identified stigma as being associated with negative affects upon the psychological, intellectual and social well-being of the chronically ill individual and their family^{1, 18}. Stigma can further produce social isolation, due avoidance in social activities and interaction in order to prevent discomfort. This can further progress to the patient having a negative self-image and self-esteem. However, stigma is experienced at different levels by different people^{1, 18, 19}.

Conclusion

The severity and impact of the disability of MS varies between patients depending on the stage of the disease and their personal experience, values and beliefs. The impact of a chronic illness can impact many lives, including members close to them. The diagnoses of MS can trigger different responses, as some people may be in denial and remain to be angry for quite some time, whereby others deal with such diagnoses positively and try to accommodate their lifestyle to the requirements in effectively managing their illness. Furthermore, illness beliefs further determine the impact a chronic condition has on the individuals' psychological and social well-being, and in turn, their quality of life. Healthcare professionals, the NHS, and support groups can effectively aid in improving patients and carers learning and understanding of how to manage the illness, which is crucial, as it will provide the patients with some independence and self-control over the condition and quality of life.

Many difficulties are experienced by MS sufferers and their carers, and one factor that contributes to their difficulties is being stigmatised and labelled by non-labelled individuals. This stigmatism can potentially lead to social isolation and can produce frustration and depression within the patient. Therefore, in order to improve the quality of life of patients and carers, it is crucial that stigma is reduced. This can be achieved by introducing interventions, increasing public knowledge and awareness of the reality and facts of living with a chronic condition like MS. Increasing the awareness of affected patients of existing support groups could further aid patients in

managing and coping with their illness and further improve any impact socially.