Caring for a person with a long-term condition



In this assignment the student nurse will analyse theimpact of a long-term conditionon an individual, significant others or the wider society. They will also analyse the role of the nurse in the management of long-term conditions, the student nurse will then compare and contrast different approaches in the management of a long-term condition. To carry out this assignment the student nurse will be using a patient who they have looked after, due to standards set out by the Nursing and Midwifery Council in The Code 2015, the Data Protection Act 1998 and patient confidentiality the name of the patient will be a pseudonym. Tom is a fifty-nine-year-old gentleman who suffers with Parkinson's, he lives with his wife, Sue. Tom and Sue have two grown up children and four grandchildren. Tom is not coping very well, as a result of his Parkinson's Tom is suffering with depression, his family are very supportive and do everything they can to help him. The student nurse will now explore the epidemiology of Parkinson's ad justify their choice of long-term condition for this assignment.

Parkinson's disease is one of the most common neurological conditions, the cause is unknown. This condition is estimated to affect up to 160 people per 100, 000. Around 1 in 7 cases of Parkinson's disease are diagnosed below the age of 60 years, Tom falls into this category. (National Institute of Clinical Excellence, 2017). In England alone there are around 121, 927 people over the age of 20 who are living with Parkinson's Disease. The prevalence of Parkinson's Disease increases with age, the prevalence is also higher in men than in women. Men aged 50-59 the prevalence is 1. 5 times higher than in women in that age group, Tom was diagnosed with Parkinson's when he was 59 so he falls into this category. The highest prevalence of Parkinson's

Disease in England is highest between people aged 75-79. As the population is growing and increasingly aging, the estimated prevalence and incidence of Parkinson's in the UK is set to grow. Prevalence is expected to rise by around 18% between 2018-2025 to over 168, 000. By 2025 the estimated yearly incidence will be expected to increase over 21, 000. By 2065 the prevalence and incidence numbers are predicted to have almost doubled. (Parkinson's UK, 2017). The reason the student nurse has chosen this long-term condition is based upon the epidemiology that has been found. There is no cure for Parkinson's disease and the cause is unknown but it is one of the most common neurological conditions and the prevalence and incidence of Parkinson's is set to rise, therefore there needs to be more research carried out to find out what causes this disease as in the coming years there will be more people living with this condition.

The student nurse will now discuss the impact of Parkinson's on Tom and his wife. Physically Parkinson's disease has had an impact on Tom as he struggles with walking, stiffness and struggles with his motor skills. Tom is overwhelmed with having Parkinson's disease and feels helpless, the Kubler-Ross Grief Cycle (1969) can be used to show how individuals cope with grief and according to this model Tom is in a depressed stage which is true, he is suffering with depression. Livneh and Antonak (2005) created linear process which focuses on individuals psychologically adapting to their condition or illness rather than grieving about it. Both models have the same aim to help individuals come to terms with their illness or condition, in both models it states that the individual will become defensive when coming to terms with their health. At the end of the Kubler-Ross (1969) model when the individual

starts to accept their condition, they will explore options and there will be a new plan in place for the individual to move on. This model seems that it would be more effective as it shows what will happen after the individual has finally accepted their illness or condition whereas the Livneh and Antonak (2005) model does not. Tom is also affected psychologically by feeling the loss of himself due to his condition. Charmaz (1983) states that illnesses become the core focus of an individual's life when they suffer with a chronic illness. This is because their lives consist of treatment regimes, periods of discomfort and medical appointments. Tom's value of his own independence and individualism come together to increase the immobilizing affects which he suffers with. Charmaz (1983) also states that chronically ill individuals become aware that they cannot do the things they valued and enjoyed in the past or cannot do these things as much as they used to. If Tom feels that he has a choice in valued activities and some freedom of action to pursue these choices, then his everyday life will not feel so restricted, his suffering will be reduced, and self-worth will be maintained. According to Charmaz (1983) individuals who suffer with chronic illnesses view dependency as negative, they also blame themselves for it. Tom is becoming more dependent on Sue and he doesn't like this he feels he should be doing everything for himself and feels ashamed that he is having to rely on somebody else. Sue has had to cut down her hours at work due to becoming Tom's carer, a lack of support leads to carers cutting their working hours, retiring earlier or giving up work completely in order to care for someone (Carers UK, 2014). This has a big impact on Sue as she doesn't have much of a social life anymore as most of her time is taken up by looking after her husband. 75% of carers say that it is hard to maintain relationships and social networks as people do not

understand the impact caring has (Census, 2011). Sue has become quite depressed as a result of her husband's health and the financial stress it is causing them both, they're both living with uncertainty of not knowing what is going to happen next. 53% of carers said their money worries were taking a toll on their health (Census, 2011). Sue's mental health has gotten worse since becoming Tom's carer as she feels guilty a lot, she feels like she could be doing more to help her husband, even though she is doing everything she possibly can. 72% of carers in the UK said they had suffered mental ill health as a result of caring according to Carers UK (2014).

The student nurse will now critically examine the role of the nurse in the management of long-term conditions. According to the Carrier and Newbury (2016), due to the increase of individuals living with long-term conditions there is a growing need to identify more innovative and effective ways of managing complex care needs. For individuals who live with long-term conditions it has been accepted that the care that they receive should be mainly in the primary and community care setting, focusing on case management for those individuals with complex needs. Community nurses are ideally placed to provide care to all individuals with long-term conditions, from health promotion, prevention and encouraging self-care to caring for people with more complex needs, comorbidities and end-of-life care. These nurses are an essential element of the multi-disciplinary team and should take the lead in delivering complex care at home to people with long-term conditions, while focusing on developing self-care, empowerment, community engagement and acting as an advocate for clients and their carers (Carrier and Newbury, 2016). When the community nurses visit Tom,

they try to educate him on his condition to help him self-manage, his wife Sue is also very involved with Tom's care and gets involved in discussions with Tom and the community nurse to help with the management of Tom's condition. When hearing about any changes to Tom's condition, the nurse can make referrals for Tom and act as his advocate, the nurse can point him in the right direction and get him the support he needs. The disadvantage to referring individuals to different services is that there is no guarantee that the individual will go ahead with their referral and attend an appointment for example but with the right information to make an informed decision on the referral the individual should understand how seeing another professional will benefit them. Queens Nursing Institute (2009) examined the role of the district nurse, district nurses aim to build therapeutic relationships and strive to promote coping and independence, both physically and psychologically. The Queen's Nursing Institute (2009) recognised that individuals with longterm conditions experience fewer exacerbations of their conditions, as a result of this the individuals then had fewer hospital admissions. Older individuals quite often have complex health needs that can change quickly, therefore it is important that the nurse educates Tom and his wife to monitor changes to his condition so that this can be closely managed, to ensure that Tom is getting the best care possible. To ensure that these individuals are safe in their home environment consists of development and delivery of individual care plans. District nurses use a broad approach towards assessment, reassessing individuals at each visit, acknowledging their changing needs and referring to other health care professionals where necessary (Carrier and Newbury, 2016). Carrier and Newbury (2016) states that the majority of individuals with long-term conditions are able to self-care

but adequate systems need to be put into place to provide case management and disease-specific care management programmes for those individuals with more complex needs. Supporting self-care involves nurses educating individuals. Individuals need to know how to self-manage and need to have the right skills. They also need to be empowered to take active part in their own care (Department of Health, 2009). When nurses educate individuals to self-manage their own condition the individual should understand the nature of their condition and understand their treatment options better which allows them to make more informed choices about their treatment. Self-management will also lead to the individual actively participating in decision-making with healthcare professionals and monitor changes to their health. (Department of Health, 2009). Parkinson's nurses provide expert care because the only individuals they work with have Parkinson's. Parkinson's nurses can support individual's coming to terms with their diagnosis. A huge part of their role is helping people to manage their medication, so that they get best results and fewer side effects. These nurses can also make referrals to other professionals such as speech and language therapists and physiotherapists. Parkinson's nurses train other professionals to ensure that individuals with Parkinson's get their medication on time in hospital (Parkinson's UK, 2016).

The Department of Health (2012) describes a long-term condition that cannot be cured but can be managed through medication and/or therapy.

Tom's Parkinson's can be managed through medication and therapy, his medication is very important as it will reduce side effects and allow the individual to get the best results. Levodopa is one of the main drugs that can

be used to treat Parkinson's and can be used at any stage of the condition according to Parkinson's UK (2015). The National Institute for Health and Care Excellence (NICE) (2017) also describes Levodopa as one of the main and most effective drugs to manage Parkinson's. NICE (2017) states that Levodopa improves an individual's motor symptoms, activities of daily living and adverse events but can lead to an increase in motor complications. Parkinson's UK (2015) says that Levodopa has its side effects and risks, when taken for a long period of time the individual can experience dyskinesia and earlier wearing off of the drug. NICE (2017) also state that if dyskinesia is not adequately managed by modifying existing therapy, consider amantadine. The problem with considering amantadine for the individual is that NICE (2017) also states that there have been no studies or evidence reporting the outcome of how beneficial this drug is for an individual with Parkinson's. If Levodopa is stopped taken suddenly then this can lead to withdrawal. Non-pharmalogical management of Parkinson's includes physiotherapy. Physiotherapy for Tom with his Parkinson's focuses on improving his physical capability and quality of movement in daily life by carrying out different activities with physiotherapists which includes walking, transferring, balance, falls education and manual activities. (Chartered Society of Physiotherapists, 2014). NICE (2017) states that physiotherapists should consider the Alexander Technique for individuals with Parkinson's disease who are experiencing balance or motor function problems. However the European Parkinson's Disease Association (2015) states that there is very little scientific evidence to confirm if the Alexander Technique is effective in Parkinson's. Practicing the technique may help with Parkinson's

symptoms such as tremor, balance, pain speech, fatigue and depression but each person will react differently to this treatment.

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