Critical review of dementia service user's experience of care

Science, Chemistry



Title: A 3000 words essay critically reviewing a service user's journey through their experience of care In this essay I will critically evaluate a resident by the name of Tom Journey withdementia. He suffers from Alzheimer's dementia and lives in sheltered housing. I will explore issues surrounding nutrition intake, wandering, communication, incontinence and theenvironmentthat affect the client, familyand staff. I will then look at the assessment process, care planning, implementing and evaluation.

I will explore patient safety, intervention and the processes that managers and professionals have to undertake when managingindividuals with dementia. These interventions and approaches adopted are vital when planning person centred care. In addition, due to the policy of confidentiality I would not mention the name of the organisation and persons involved. The essay will end with a conclusion and a summary. According to Mathers and Leanardi (2000), "Dementia is a syndrome caused by a range of illnesses and currently many are incurable, and cause progressive, irreversible brain damage.

They include Alzheimer's disease (the most common cause), vascular disease, frontal lobe dementia and Lewy Body disease. Symptoms of dementia can include memory loss, difficulties with language, judgement, insight andfailureto recognise people, disorientation, mood changes, hallucinations, delusions, and the gradual loss of ability to perform all tasks of daily living", (Mathers and Leanardi, 2000). Mace and Rabin (1999) highlighted that, "the word dementia originated from two Latin words which

mean "away and mind". This can indicate a loss of memory inability to function effectively, which can result in mental confusion".

lack is a seventy year old man with dementia. He lives in sheltered housing. He has four children two sons and two daughters. He was moved from his home into sheltered accommodation after the death of his wife Mary. His condition deteriorated very rapidly and he needed extra support to live at home safely. The family was unable to adequately provide for Jack's needs, so they decided to re-house him. The family brought lack with them to view the flat before he was moved in. This allowed Jack the opportunity to meet the staff and get familiar with the new environment. He was brought in by is son and daughter, but his son stayed with him in the guest room for a few days to get him settled and feel comfortable. Jack was showing early signs of dementia as his communication was not clear at times and often his speech was muddled. Furthermore, his memory was poor at first as he kept asking for his wife repeatedly for examples, " where am I", " whose house is this", and "why am I here". Also his nutrition was an issue as he was not eating his meals and often said he was not hungry or he would eat later. He would sometimes say take it away and feed the pigeon.

Foodwould turn up in various places like bins, in drawers and even in his bed. Mace and Rabins (1999) mentioned that eating alone can contribute to or worsen their confusion. Incontinence was also a big concern for staff as he was constantly wet and soiled with faeces. He would choose places not suitable to use for toileting, removing his protective clothing. He was also hiding dirty soiled clothes in inappropriate places. Moreover, getting his

personal care done was a big task as he was not cooperative. Beatie et al, (2005) stated that people with dementia do not know that they are not being cooperative with certain basic tasks.

This could be related to my client as I observed these issues on many occasions. All these conditions have been highlighted by (Kitwood, 1997). With regard to incontinence, Parker (2000) supported that because of the dying of the brain cells, a person like Jack will not be able to independently identify the message the brain is conveying about the bowel. This problem was identified with Jack. Jack, as supported by Parker (2000) should be encouraged to use the toilet before and after consuming meals and drinks and should also have a regular pad change.

Parker 2000 also cited that when any person in a state like that of Jack is constipated or having sluggish bowel movement, they should be offered medication like suppositories and if this does not work they should be supported byobservation. When dealing with Jack who does not have mental capacity it is important to observe his actions. When he is in need of toileting he can exhibit the following actions which are non verbal such as pulling down or removing pants, or opening his fly. These actions are likely to suggest that he wants to use the toilet.

Mace and Rabins (1999) argued that it can be very difficult for practitioners to achieve appropriate assessments when they are dealing with persons who are living in an independent setting. My assessment highlighted many problems such as personal care, poor memory, poor nutrition intake, urinary incontinence, poor communication and wandering about all the time.

However, this was more pronounced in the evenings. Morris and Morris (2010), Kitwood, (1997) and Algage (2006), have highlighted this problem to be "sundown syndrome".

According to Leblance (2011) he described this as onset of confusion that occurs in late afternoon and night time. Algage (2006) further stated that wandering is a way of communicating in a non verbal form by using action to correspond with others. Moreover Beatie et al, (2005) argued that patients with dementia may not be able to read signs. For example factors like the environment may cause them to be distressed and might put them at risk, (Hodgkinson et al, 2007). Some residents like Jack may have limited communication ability to verbalise what they want to do, so they just show action as a way of communicating.

For example, the sign posts, symbols and photographic pictures might not appeal to them because of their limited ability to focus on details, (Hodgkinson et al, 2007). Beatie et al, (2005) and Fox and Wilson (2007) have highlighted that living in a sheltered housing environment can be a lonely experience for many patients and this can make them feel isolated. More so, Beatie et al, (2005) mentioned that these factors might cause a patient to wander because if they feel lonely and anxious for a long period of time. They might want to find something to engage in.

A person with dementia might find it difficult to sit down. For example in my observations I feel that Jack was living in a community where he had friends and family to socialise with and moving to a new place was somehow upsetting for him. Likewise changes might have caused Jack's more loss of

memory and this could be another reason why he failed to adjust to his new surrounding as cited in Mace and Rabins (1999). Moreover, in this sheltered housing there are no facilities like shops and recreational facilities as it is in a secluded area.

Knockers (2000) mentioned about daily living activities that could have been useful to a patient with dementia like Jack. In my opinion, this would have given Jack the opportunity to engage with other residents. This would have been a great way of socialising, chatting, enjoyment and given him a purpose in life and most of all engaging his time and stop him from wondering so frequently. According to Cheston and Bender (1999) and Innes et al, (2000) the DCM (Dementia Care Mapping) is a precise framework that is important to assess patients with dementia.

The DCM (Dementia Care Mapping) is an observational tool which is used in a professional setting. This tool could have been useful to Jack if he was living in suitable housing that meets his needs (Kitwood 1997, Shels 2007 and Fox and Wilson, 2000), Mace and Rabins (1999) mention that MME (Mini Mental Examination) also known as the "mini mental" is one of the tools that are used to screen an individual's mental ability at the onset of dementia. This tool is also known as the performance tool that allows five minutes to perform a set of precise tasks.

This entails a maximum score of thirty answers to questions given. "Some of the questions are, do you know what day it is, date, month and the time, do you know what country you live, and the town. Can you spell the word "world" backwards, can you write a sentence". Likewise, In Jack's case he was

assessed using this tool to get a precise answer to see what he can independently do for himself. In addition, Fox and Wilson (2007) argued that the assessment processes should be compiled into a feedback statement. This information should be given at the beginning and end of the assessment.

Chester and Bender (2000) mentioned that feedback should be given in both oral and written statement. This is necessary for the patient and their family to adjust and come to terms with their illness, and deal with their emotions. According to Carmody and Forester (2003) the main areas of care planning are assessment, planning, evaluation, implementation and evaluation. Care plans are legal documents which should be reviewed on a regular basis for accuracy. Jack's care plan contains some important information such as his name, date of birth, address and all information recorded was signed and dated.

Likewise, May et al (2003) mentioned that a care plan should be compiled and put together the persons needs and deeds. Jack's care plan was fully supported and some of the information included was his life history, lifestyle, health, personality, and preferences, present and future wishes. Jack's capacity, cognitive ability and the stages he was at present were documented. Jack's care plan contains three columns. The left column was to record Jack's needs, the middle column gives precise information for cares to comply with, whilst the right column is to record information, sign, date and reviews (May et al, 2003).

May et al, (2003) proposed that the enriched care planning was developed from the enriched model of dementia by (Kitwood, 1997). Jack care plan consists of five core areas which are reviewing, profiling, implementation, identifying needs and documenting needs. Jack care plan was fully supported by the carers. In Jack's case his care plan was reviewed with the social worker, general practitioner, occupational therapist, dietician, warden, care manager and family and myself who is his key worker. This set out clear instructions for staff on how to personalise care for Jack.

This includes, monitoring and assessing changes in his toileting, nutritional intake, communication, health and wandering. Four main calls were put in place for his main meals and regular checks to stop him from feeling lonely. Jack care plan was reviewed and implementation of safety devices was put in action to keep Jack safe. This involves the implementing of sensory aids and equipment that will help to keep him safe at all times and especially during the nights. This included a bed sensor and door activator that goes off when he gets out of bed and when he leaves his flat.

This equipment was most useful during the nights. Reflective lighting was also put into place. It would come on at a certain time in the evening. The door bell flashing light let him know when someone was entering his flat. Picture coding colour was put on his fridge door and bedroom door to remind him where to go and what to do. Jacks' family were in complete denial about his condition and they would often get very upset with him. They thought that their dad was trying to get back at them for moving him. One daughter was constantly fussing over him and telling him off.

This made it quite difficult for staff and management to get the assessment process started. The other barrier was the staff members that were not able to support Jack's family appropriately, as they were not trained adequately in dementia care. Jack's condition deteriorated rapidly and staff was finding it quite difficult to cope with his demanding and stressful behaviour. Jack was given tablets to keep him calm, however, this medication in my observation was too strong for him and often he would sleep for long periods of time.

Staff would have to wake him up for meals and before he finished his meals he would be fast asleep. In work places which are independent based, these facilities are not designed to accommodate people with certain forms of dementia and for this reason it took a longer time for Jack's needs to be reassessed. Jack's needs were finally met and then he was admitted to a dementia unit where he was housed, (Carmody and Foster, 2003, Jacques and Jackson, 2000). These factors can become a barrier for professional when implementing care for people living with dementia, (Jacques and Jackson, 2000).

In Jack's case he could have benefitted from the evaluation tool to stimulate communication between staff and himself. This would have prompted his alertness and encouraged communication at meal times as observed by Shiels (2007). With reference to evaluation this process is necessary to get a direct result of Jack's illness. This will establish how far his condition has deteriorated and the extent of his impairment and functioning. Moreover, this will identify other health problems, so that the necessary treatment and planning can be put in place to address his needs, (Mace and Rabin 1999).

Jack had to undertake this evaluation and many tests such as CBC (Complete blood count) which includes a blood chemistry test, checking the liver and kidney for signs ofdiabetes, vitamin B12 and thyroid level. The VDRL check for syphilis and LP (lumbar puncture) investigates the central nervous system. EEC (electroencephagram) measures the brain activities. CT scans, MRI scans, PET scans, SPECT scans which are all important tests can identify the presence of a stroke. Jack was also given a neuropsychological test or the cortical test where they test his memory for writing and reasoning ability, and coordination (Mace and Rabin 1999).

A psychiatric and psychosocial evaluation was also conducted by way of interviews with Jack's family and his friend. This was vital to planning and development of care and this was also supported by a family evaluation to assess and to address their emotional, financial and physical needs, (Carmody and Forster 2003). Jack's condition has deteriorated even further and he has started leaving the premises through the back door. There is sensory equipment which is now in place in order to monitor his movements.

Jack sometimes presses the button and it raises an alarm with the central control office. The control room staff will then contact the staff on duty to go and attend to Jack and see whether there is anything he needs. In most cases when the staff gets there, Jack will be trying to leave the premises not properly dressed. Examples being dressed in his pyjamas and bed room slippers, wearing a vest without his shirt or wearing his trouser inside out. When the staff try to get Jack to return to his flat he becomes very aggressive, shouting and hitting the staff and refusing to go back.

The police on many occasions are called to search for him. AGASE (2006) indicated that wandering is associated with risk factors of getting lost and falls. As highlighted by Hodgkinson et al (2007) " gridlines placed on front door exits, door handles, panic button bars might be an effective way to addresses Jack's wandering and reduce the risk of escaping". Carmody and Forster (2003) suggest that a person like Jack can benefit from ADL (Activities of Daily Living) as this will help test his functioning abilities and performance.

With regards to communication and Jack's outburst Phillips and Penhale (1996) argued that some people with dementia like Jack might have poor memory, limited communication ability with others. Jack is unaware of his aggression towards staff. This is not done intentionally as his brain cells are dying. Jack is unaware that he is causing harm to any one as he is simply trying to communicate. Jack will be trying to say why are these people stopping or preventing me from going to see my friends. In my observation Jack was finding it difficult to say the right word, as he was not able to understand what is being said to him.

Carmody and Forster (2003) Fox and Wilson (2000) highlighted that the person who is undertaking a communication assessment needs to be a good listener and a competently trained professional. This person needs to have experiences of in dealing with different cases of dementia and know the differences between the different types. Fox and Wilson (2000) mentioned that a person with counselling skills might be able to address the needs of a

person with dementia more efficiently. In my opinion, these skills are important when working with customers with dementia.

In Jack's case this would have been more beneficial if staff dealing with him had appropriate counselling skills. They would have been in a position to understand how to communicate with Jack as to achieve effective results. In the long run Jack was finding it more difficult to cope with every day activities. He had suffered a relapse and his condition deteriorated very rapidly and he needed more specialist care. He was not coping well and his health and safety was at risk. Jack needs were reassessed and he was no longer capable to live independently any more.

Management and social worker were in the process of getting him relocated when he suffered a fall. He was taken to hospital and then he was moved into a residential home that cares for people with dementia. In conclusion, the government acknowledges dementia as a growing problem and has put strategies in place to care for people with dementia. To address Jack's needs appropriately his care should be person centred. Jack was moved to a new home and this might have contributed to his wandering. His new setting was secluded and he had no friends to communicate or socialise with.

This factor could have led to further confusion and made him feel lonely and even depressed. Although Jack was fully supported by the planning, assessment, implementing and evaluation process, his needs were slow to be addressed by the family and this posed as a barrier to Jack getting the care he required. However, the assessment procedure and progress for independent living have to be organised by many professionals. It appears in

Jack's case it was not recognised and dealt with appropriately at times. For example, the process to get a person assessed for dementia in independent housing took a long time.

There were other issues and barriers that Jack faced on his journey, even though the government had put these strategies in place to address the needs of people with dementia. In order to address Jack's needs and that of other people with dementia the professionals need to adapt a person centred approach. Staff needs to be competently trained in dementia care so that they can support family and friends when a person is diagnosed with dementia. Reference Algase, D. L. (2006) What's new about wandering? An assessment of recent studies 226 -234 [Available at: www. reo. beds. ac. uk]. (Accessed: 3/10/ 2011). Beatie, E. R. A. Song, J. And LaGore, S. (2005) A comparison of wandering behaviour innursinghomes and assisted living facilities, Research and theory for nursing practice Vol 19 No. 2. 181-196 [Available at: www. breo. beds. ac. uk]. (Accessed: 3/10/2011). Carmody, S. Forster, S. (2003) Nursing older people; a guide to practice in care home. Oxion Radcliff Publishing. Cheston. R. Bender, M. (1999) Understanding dementia: the man with the worried eyes, London. Jessica Kingsley. Fox, M. And Wilson, L. 2000) The centred advocacy for people with dementia, The journal of dementia care Vol 15 No 2. Jacques, A. And Jackson, G. (2000) Churchhill Understanding dementia. 3rd edn. London. Livingston. Hodgkinson, B. Koch, S. Nay R. And Lewis, M. (2007) Managing the wandering behaviour of people in a aged care facility 407-436 [Available at: www. breo. beds. ac. uk]. (Accessed: 3/10/2011). Inness, A. Capstick, A. And Surr, C. (2000)Mapping out framework, The Journal of dementiacare, Vol. 15

Kitwood, T (1997) Dementia reconsidered; The person comes first, Buckingham.

Open University Press. Knockers, S. (2007) Capturing the magic of everyday activities, The journal of dementia care. Vol 15 No2 Leblanc, G. J. (2011) staying afloat in a sea of forgetfulness; common sense care giving, Bloomington Xlibris. Parker, T. (2000) Incontinence of faeces: the final frontier? Journal of dementiacare VOL. 8 No2 Phillips, J. and Penhale, B. (1996) Reviewing Care Management for Older People, London. Jessica Kingsley Publishers May, H. Edwards, P. And Brooker, D. (2009) Enriched care planning for people with dementia, London. Jessica Kingsley