Dementia care in the U.K: Critical analysis of the current care pathway using an individual case study

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This individual care pathway discussed in this article concerns an elderly gentleman who was diagnosed with a multi-infarct vascular dementia fifteen months ago. In accordance with the NMC Code of Conduct (NMC, 2008) he shall be referred to with the pseudonym of Mr Smith to protect his confidentiality. Mr Smith is currently in secondary care in the south of England and attends the memory club on a weekly basis where Cognitive Stimulation Therapy (CST) is delivered by both nurse trained and untrained NHS employees. Mr Smith lives at home with his wife who is his primary carer. Mr Smith's symptoms include difficulties with short term memory recall, and disorientation to time and place.

Introduction

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Dementia in the U.K

'Population ageing is one of humanities greatest triumphs. It is also one of our greatest challenges' (World Health Organization, 2001, p6).

There are currently 700,000 people in the UK with dementia, of whom approximately 570,000 live in England. Dementia costs the UK economy £17 billion a year, and in the next 30 years the number of people with dementia in the UK is set to double to 1.4 million, resulting with predicted costs trebling to over £50 billion per year (Department of Health, 2009). With the aftermath of the recession and the austerity measures this meant for our health services still lingering, this poses a challenge of epic proportions for our government if services are to step up to the mark and improve dementia services in order to cope with the significant predicted increase in need. In response, in 2009 the Labour government published 'Living well with dementia: A National Dementia Strategy' which was created with the intention of becoming a catalyst for change in the way that people with dementia are viewed and treated in England by identifying 17 key objectives to be implemented, largely at local level (DH, 2009). But three years on, is this being implemented and if so is it effective?

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Much work remains to be done regarding the long term evaluation of the strategy as the economic impact assessment was modelled over five years, and even then it was acknowledged that there was no expectation that all of the areas would have been implemented by this point (DH, 2009). However, what this article has to offer is a closer look at the individual and current pathway of a gentleman with dementia to ascertain whether this corresponds to policy, safety, inclusion of both patient and carer in care planning, and person centered care.

The role of the mental health nurse

"Treat people as they are, and they will remain that way. Treat them as what they can be, and you help them become what they are capable of being" (Goethe, 2011)

In the multifarious and complex role of the nurse individuals and multidisciplinary care teams are entrusted with the wellbeing, health and happiness of those in their care. How they conduct themselves is essential to their integrity, and the wider nursing profession in its entirety. The Nursing and Midwifery Council (NMC) states that nurses and midwives must use their professional knowledge, judgment and skills to make decisions based on evidence for best practice and the person's best interests (NMC, 2009). It is through a combination of obligatory professional accountability, the choice to work in the caring profession, and indeed our very humanity itself that those in the caring profession strive for optimum practice and safe individualized patient care. These individuals are ethically responsible for the rectitude of their actions, which impact upon our pride in their work, and upholding the profession and public confidence in nursing and the National Health Service (NHS).

Conduct and a quality based, dignified ethos of care applies to every branch of nursing and to people in every stage of life from birth to death, with dementia care being no exception. As pointed out by the World Health Organization's policy framework Active Ageing (2002), 'yesterday's child is today's adult and tomorrow's grandmother or grandfather' (p12).

Dementia assessment

Dementia is a terminal condition that results in a progressive decline in multiple areas of function, including memory, reasoning, communication skills and the skills needed to carry out daily activities (Department of Health, 2009). The International Classification of Diseases (ICD, 2010) defines multi infarct vascular dementia as 'the result of infarction of the brain due to vascular disease, including hypertensive cerebrovascular disease. The infarcts are usually small but cumulative in their effect. Onset is usually in later life' (ICD, FO1).

Mr Smith initialized his care pathway when he and his wife visited his general practitioner (GP) to express concern over his memory. Whilst indications of a potential memory deficit were relatively mild at this point, such as having difficulty recalling details of recent events, his wife of 53 years was sensitive to the changes and naturally concerned. Although perhaps seemingly insignificant this first step is incredibly valuable and consequential, as the World Alzheimer Report (2011) identified lack of detection as a significant barrier to improving the lives of people with dementia. During his primary care assessment Mr Smith underwent a standardized 'dementia screen' to rule out other causes, which includes routine hematology, biochemistry tests, thyroid function tests and serum vitamin B12 and folate levels. This assessment was in adherence with the National Institute for Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE) guidance on dementia care (2006, updated 2010) therefore demonstrating safe and correct practice.

Having summoned the courage to seek assistance regarding his memory, both Mr Smith and his wife were fully engaged in the screening investigations and were willing participants throughout the process. Potential care pathways were explained and Mr Smith and his wife (after Mr Smith consented to his wife's involvement) were actively involved in choosing and planning further potential care options. Once alternative causes for the symptomology had been ruled out Mr Smith's GP discussed the transfer of his assessment onto secondary care and with Mr Smith's consent and agreement sent a written letter of referral to a psychiatrist in the Memory Service in his local Primary Care Trust (PCT), who then arranged a home visit for assessment. Valid informed consent was sought at each juncture of assessment and information sharing. Where someone lacks capacity to consent then healthcare professionals must refer to the Mental Capacity Act (2005) in order to legally make decisions in the individual's best interests. Transfer of care is subject to strict confidentiality protection in accordance with the Data Protection Act (1998) which applies numerous data protection principles upon sharing information which must be lawfully abided by.

The psychiatrist who subsequently visited Mr Smith and his wife at home was congenial in his manner in order to alleviate Mr Smith's initial apprehension and the less formal components of the assessment were deliberately done first. Both assessment and care planning aspires to being holistic, which the NMC defines as: considering the whole person; taking physical, social, economic, psychological, spiritual and all other relevant factors into consideration when assessing, planning and delivering care (NMC Glossary 2010). Mr Smith received a comprehensive assessment including: history taking, Mini-Mental State Examination (explored in further depth later), physical examination and a review of current medication to identify any that could be adversely affecting his cognitive functioning. This assessment also remained concordant with the NICE guidelines, although two possible further functions of the assessment were omitted with Mr Smith's case. First was the use of structural imaging, such as magnetic resonance imaging (MRI) or computed tomography (CT) to exclude other cerebral pathologies and establish the subtype of diagnosis. As Mr Smith had a history of heart transient ischaemic attacks (TIAs) the psychiatrist was sufficiently satisfied that his sub type was vascular in origin, however the final decision was left to Mr Smith, and after a full explanation he agreed a brain scan was unnecessary. Secondly, and also due to the nature of the diagnosis, the psychiatrist did not offer any pharmacological intervention. Whilst three acetylcholinesterase (ACEhE) inhibitors are recommended for the management of mild to moderate Alzheimers, and another NMDA-receptor antagonist against moderate to severe Alzheimers in the current British Nursing Formulary (BNF, 2011), these should not be prescribed for cognitive decline in people with vascular dementia (NICE, 2011).

Delivery of the dementia diagnosis

All aspects of the assessment, including the investigations and interventions that were unsuitable for Mr Smiths given diagnosis were explained to him and his wife in an appropriate non-jargon manner at a pace that allowed them to competently comprehend. Before sharing his professional opinion as to the underlying cause of the deficits in memory illustrated throughout the holistic assessment the psychiatrist asked if Mr Smith would like to know, thus sharing empowerment between them and reducing the boundaries between psychiatrist and patient. As Tom Kitwood recognized in his influential work regarding redefining dementia care and recognizing personhood 'those who have dementia are equal members of the human race with the rest of us. We are all persons, and all, fundamentally, in the same boat (Kitwood, 2000, page 9). The impact of a dementia diagnosis depends greatly upon how it is made and imparted (World Alzheimers Report, 2011) and the psychiatrist was careful to deliver Mr Smith's diagnosis in a sensitive and professional manner. The immediate options and support pathways were explained with care not to overwhelm Mr Smith with information at this point as receiving a diagnosis of dementia can be a challenge for both those who are newly diagnosed and their families or carers (NICE, 2010). In adherence with the dementia care pathway of the NHS trust that was treating Mr Smith, he then received a post-diagnostic community visit with a trained community psychiatric nurse (CPN) who discussed the options open to him once he had been given a little time to accept the diagnosis. To assure safe transfer from primary to secondary services (regarding this particular diagnosis) and continuity of care the psychiatrist sent Mr Smith's GP a summary of the assessment; and they will continue to share all relevant contact pertaining to Mr Smith's dementia in order to ensure safe practice, as stipulated in the NICE guidance (2010).

Mr Smith was given clear and uncomplicated information on his new diagnosis and his allocated CPN was able to answer any questions that he or his wife had at that time. Whilst the post diagnostic counselling is limited to one or two sessions adequate information and contact details are left so that Mr Smith is able to get further support, or request an assessment of his needs or indeed those of his wife, as his main carer, at any time. Recognition has grown for carers in the last decade with the 2008 Carers Strategy: '*Carers at the heart of 21st-century families and communities*' supporting legislation to give carers the right to an assessment of their own needs which was further supported with the new coalition governments '*Next Steps for the Carers Strategy*' published in November 2010. Mr Smith's perspective, and that of his wife, were continually respected and all nursing interventions were explained and planned in partnership with them, which adheres to the Standing Nursing and Midwifery Advisory Committee's guidance, *Caring for Older People: A Nursing Priority* (DH, 2001).

The use of Cognitive Stimulation Therapy (CST) for the treatment of dementia

Of the further care options, Mr Smith accepted the offer of attending the Memory Club, which delivers Cognitive Stimulation Therapy (CST) on a weekly basis at a local venue. CST is an evidence based therapeutic intervention which is delivered by NHS nurses and support workers, the structure of which is outlined below in Figure 1. CST has been evidenced as beneficial for maintaining cognitive function for people with dementia (Brooker, 2007; Spector 2006; Woods et al 2006) and has been found to improve quality of life (Woods et al, 2006). Furthermore CST has been compared to psychopharmalogical interventions for both efficacy and cost effectiveness and has been found to have similar benefits with both aspects (Spector, 2006). Knapp et al (2006) found that when comparing costs of people receiving CST and people receiving usual care there was little difference, but that CST yielded greater improvements in cognitive functioning and quality of life. Both efficacious treatment and cost effectiveness is crucial in our current times of austerity as the average annual societal cost per person with dementia is almost £21,000 (WHO, 2011), and as noted earlier with the number of people with dementia set to soar to 1.4 million over the next 30 years this is set to have a substantial impact on the economy. As David Behan, the Department of Health's Director General for Social Care, Local Government and Care Partnerships, highlighted in his blog on 'improving dementia services' made on January 4th 2012, 'we are facing a significant rise in the amount of people experiencing dementia and if we are going to respond to that increase then we need to accelerate progress and development in relation to dementia services' (Brehan, 2012).

An Introduction to Cognitive Stimulation Therapy

CST was designed through systematically reviewing the literature on the main non-pharmacological therapies for dementia. The most effective elements of the different therapies were combined to create the CST programme, which was then evaluated as a multi-centre randomised controlled trial (RCT) in 23 centres (residential homes and day centres) in 2003. The results of the trial showed that CST led to significant benefits in people's cognitive functioning, and further research showed that CST made a significant impact on language skills including naming, word-finding and comprehension.

CST treatment involves delivering sessions of themed activities. They were originally designed to run twice a week over a seven week period. However, people often prefer to run groups once a week and offer a longer-term programme, which involves repeating sessions and offering new sessions as outlined in a new treatment manual. Sessions aim to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group. CST treatment can be administered by anyone working with people with dementia, such as care workers, Occupational Therapists or nurses and can take place in settings including residential homes, hospitals or day centre's.

Figure 1. An introduction to Cognitive Stimulation Therapy (adapted from www.cstdementia.com)

Assessing health risk in dementia care

Another important aspect of holistic assessment is assessing for health risk, an imperative component in dementia care in light of the anticipated strain on the health services. Risk covers multifarious areas including immediate health risk, health promotion and disease prevention. Incorporated into Mr Smith's holistic assessment was a standardized Clinical Risk Management Tool (Morgan, 2000). Morgan defines risk management as 'a gathering of information and analysis of the potential outcomes of identified behaviours and identifying specific risk factors of relevance to an individual, and the context in which they may occur' (page 2). As with the rest of the assessment Mr Smith was actively involved with the process of gathering information, and also consented for his wife to contribute, so that patient, carer and psychiatrist were all equal and the experience was more of enlightenment than interrogation for Both Mr Smith and his wife, and no major risks were identified for him at this point. Mr Smith was also offered an assessment with an Occupational Therapist (OT) who could make alterations in his home to reduce risk, he declined at this juncture but remains entitled to OT assessments in the future.

Mr Smith's diagnosis of vascular dementia means that he has the potential to control underlying conditions that may exacerbate his condition. Mr Smith used to smoke and had a history of high cholesterol, both risk factors for vascular dementia, however due to education and wellbeing promotion he now no longer smokes and ensures that he maintains low cholesterol levels. Equivalently these and other strategies can be used to assist disease prevention, specifically with vascular dementias, which could help in the prevention or delay in onset of the disease. Other risk factors for vascular dementia include high blood pressure, diabetes and lack of exercise, all of which are treatable to a degree (www.dementiatoday.net, 2011). *The Dementia Strategy* (DH, 2009) has a strong emphasis on health promotion and even generates the slogan 'what's good for your heart is good for your head' (page 24) and only last month the Alzheimer's Society published a discussion conducted by 130 scientists in America to initiate prevention trials which would address known risk factors and intervene at very early stages of the disease. If the UK and the world are to effectively manage and even improve dementia care over the next decade then surely health promotion and disease prevention are the quintessential components.

Putting patients at the centre of their care

The Care Quality Commission (CQC) discovered when researching for their five year dementia care plan that patients and carers wanted more value placed on their experience and views of dementia (CQC, 2010). In order to achieve this care needs to become individualized, or person centered. Both NICE (2011) and the CQC (2010) emphasize the need for person centered care, which involves considering the perspective of the person with dementia and their carers, embracing the individuality and nuances of different people and respecting their human value regardless of age or cognitive ability. Kitwood (2000) agrees, and believes that it is essential that we respect people's diverse, idiosyncratic and elaborate personal experiences of dementia. Person centered care is part of the phenomenological school of psychology (Brooker, 2007), which can put it at odds with the medical model, as this is only concerned with phenomena that are measurable and quantifiable (Zigmond, 2010). However, modern approaches to psychiatry are no longer restricted to a biochemical or neuropsychologocal point of view and now include social sciences and other approaches that reflect the development of psychopathology over the last century (Lemma, 2000). As an anonymous AMHP blogger 'Cb' wrote in one of his pieces before he had to shut down his site, perhaps trying to fit all situations into previously presented 'models' is at odds with the need to think creatively and individually (Cb, 2010). The same author also proposed a 'recovery model' for dementia, explaining that recovery is not necessarily about 'cure' or getting back to the place one was prior to diagnosis but more as working towards an optimum with the person at the centre of their own care and decisions. Conceivably greater accreditation could be given to theories compared to models, such as Peplau's theory of interpersonal relations, first published in 1952 (see figure 2). This considers nursing an interpersonal process that is both therapeutic and a healing art and perceptibly embraces the same ideology as person centered care.

Peplau's Theory of Interpersonal Relations

The four components of the theory are: person - which is a developing organism that tries to reduce anxiety caused by needs; environment - which consists of existing forces outside of the person in the context of culture; health - which implies forward movement of personality and other human processes; and nursing – which functions cooperatively with other human processes to make health possible for individuals in communities.

The nursing theory identifies four sequential phases in the interpersonal relationship:

The orientation phase defines the problem, which starts when the nurse meets the patient. After defining the problem, the orientation phase identifies the type of service needed by the patient and is essentially the nurse's assessment of the patient's health and situation.

The identification phase includes the selection of the appropriate assistance by a professional. The patient begins to feel as if he or she belongs, and feels capable of dealing with the problem which decreases the feeling of helplessness and hopelessness. The identification phase is the development of a nursing care plan based on the patient's situation and goals.

The exploitation phase uses professional assistance for problem-solving alternatives. The advantages of the professional services used are based on the needs and interests of the patients. In the exploitation phase, the patient feels like an integral part of the helping environment, and may make minor requests or use attention-getting techniques. This phase is the implementation of the nursing plan.

The final phase is the resolution phase. It is the termination of the professional relationship since the patient's needs have been met through the collaboration of patient and nurse. This can be difficult for both if psychological dependence still exists. The patient drifts away from the nurse and breaks the bond between them. This is the evaluation of the nursing process and whether the set goals have been achieved or not.

Figure 2 . Peplau's Theory of Interpersonal Relations (www.nursing-theory.org)

Regardless of doctrine the philosophy governing all care should be that it is tailored to the individual, acknowledging and appreciating their views and the lived experience of the patient and his/her carer with safety underpinning all practice.

Critical analysis of the Mini Mental State Examination (MMSE)

The widely used Mini Mental State Examination (MMSE) was used to assess Mr Smith's cognitive abilities which is a short series of questions which measure cognitive ability over a range of functions such as memory and language (see figure 3 for cognitive domains tested). Mr Smith scored 26/30 when originally assessed by the psychiatrist, he lost two marks for orientation to time, one for orientation to place and one on recall. On his last assessment at the Memory Club he scored 25/30, losing two marks for orientation to time, two for orientation to place, and one for recall. From his MMSE scores Mr Smith appears to be retaining the majority of his cognitive functioning abilities and has only dropped one mark over the past fifteen months.

Despite its widespread usage the quantitative nature of the MMSE is contradictory to the modern ethos of person centered care, amongst other limitations. Constructed in 1975 the creators Folstein, Folstein and Hugh claimed the MMSE to be quick, acceptable to patients and testers, and both valid and reliable. However more recently in 2008 Crinelli and Ostberg retested the reliability and validity and found from their contextual analysis that the MMSE had low reliability, too many easy items, too many cutoff points and lack of standardized scores and concluded that the MMSE should not be used on its own for cognitive screening assessment. Although they did acknowledge that the parameters for validity and reliability have changed since the test was published (Crinelli and Ostberg, 2008). What is of further magnitude was the small sample sized used to originally test the MMSE, only 33 patients from one of the sample were retested, and only 24 of those were compared with an age matched sample. Furthermore Sid et al (2008) found that the MMSE cut off point score of 24 does not yield optimal classification accuracy with highly educated individuals and instead suggested a more stringent cut off score of 27 for people in this category; and Scazufa et al (2008) discovered whilst the MMSE was adequate for screening older adults with minimal literacy skills, misclassification was unacceptably high for older adults who are illiterate, which yields high consequences for the use of the original tool in middle income countries where illiteracy is high.

Guerrero-Berroa et al (2009) found that orientation for time was the only MMSE domain for which poor baseline performance was significantly associated with a faster rate of overall cognitive decline, however, this is of relevance to Mr Smith as he dropped two points for orientation to time both on his initial and his most recent MMSE. A meta analysis of over 42 studies concluded that MMSE offered only modest accuracy and was best for ruling out dementia in primary care, however the potential for bias as a variable subject demographics may have introduced heterogeneity. Ostensibly it would appear that whilst the MMSE has numerous limitations it should only be considered as part of a much wider holistic assessment, which Wind et al (1997) were in agreement with, as they concluded that diagnosis should be based on an individual's overall clinical picture.

Mini-Mental State Examination - A brief screening tool to provide a quantitative assessment of cognitive impairment and to record cognitive changes over time.

- The MMSE consists of 11 simple questions or tasks grouped into 7 cognitive domains
    - Orientation to time
    - Orientation to place
    - Registration of three words
    - Attention and calculation
    - Recall of 3 words
    - Language
    - Visual construction.
- A possible score of 30 is used to provide a picture of an individuals present cognitive performance based on direct observation of completion of test items / tasks.
- A score of <24 is the generally accepted cutoff indicating the presence of cognitive impairment (Dick et al. 1984).
- Levels of impairment have been classified as: (Tombaugh & McIntyre 1992):
    - None: score = 24-30
    - Mild: score = 18-24

Severe: score = 0-17

Figure 3. Cognitive domains tested in the MMSE (adapted from http://www.rehabmeasures.org)

Evaluation of the dementia care pathway recommendations for the future of dementia care

Research of Mr Smith's care pathway and subsequent comparison to contemporary policy, research and guidance indicate the standard of care he experienced to be up to date and notably endeavoring to become person centered. It is invigorating and motivational to observe the beginning of the shift in power from health professional, regardless of rank, to that of a shared partnership of care planning with both patient, family and carer/s. Whilst this was merely a single case of care and dementia care has a long way to go both nationally and internationally, it is a step in the right direction. The ethos underpinning the *Dementia Strategy* (2009) is compelling but naturally quite formidable as it is requires such an expansive overhaul of services, plus the added pressure of the predicted rise in people accessing dementia care can make the task at hand somewhat overwhelming. But as has been recognized, the crucial fundamental element to improving quality of life for older people and reducing the strain on the NHS is the promotion of wellbeing and disease prevention, which are united together. Therefore responsibility for the fate of our services, and indeed our parents, grandparents, and perhaps ourselves, rests with everyone to promote dementia awareness and implement wellbeing in our everyday lives. Ongoing research is essential into person centered, efficacious and cost effective therapeutic interventions for dementia care. Meanwhile those working in the field of dementia, or nursing in any domain, are responsible for taking pride in continually improving themselves through reflective practice, after all, as Frankfurt said of free will in 1969 (cited in Watson, 1982) 'no other animal other than man, however, appears to have the capacity for reflective self evaluation' (page 83). We have so many skills and qualities unique to our species and unique to each individual that we can appreciate on both sides of the dementia care coin, both in the betterment of our nursing qualities, and the appreciation and celebration of the qualities in others, regardless of what stage of life they are in.

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