DISCLOSING A DIAGNOSIS OF DEMENTIA: A BACKGROUND TO THE PHENOMENON

Gary Mitchell and colleagues explore the potential benefits of providing timely diagnosis to people with dementia and in particular how nurses can support them and their families.

Abstract

The number of people with dementia who have not received a formal diagnosis is high, in the UK and also internationally. Government strategies aim to raise public and professional awareness about the condition and increase rates of timely diagnosis. Benefits associated with timely diagnosis include earlier access to medication and being able to plan future care. Despite these benefits, a number of factors contribute to delay in, or in some cases denial of, diagnosis to people with dementia.

This article aims to provide nurses, who are important healthcare professionals in the diagnostic process, with an overview of the literature on disclosing diagnosis to people with dementia.

Keywords

Advocacy, Alzheimer’s disease, dementia, diagnosis, diagnosis disclosure, person-centred care

THERE ARE significant differences in the percentage of people with dementia receiving a diagnosis in England, Wales and Northern Ireland. In 2012, for example, it was estimated that 39 per cent of people in Wales had a diagnosis, 44 per cent in England and 63 per cent in Northern Ireland (Alzheimer’s Society 2013). As a result, the prime minister’s challenge on dementia (Department of Health (DH) 2012) aims to increase diagnosis rates by two thirds by 2015. The Scottish Government (2013) has launched a similar initiative.

While not everyone will want to receive a diagnosis, there are a number of people with dementia who are not able to make this decision because of a range of factors including (DH 2001, 2005, Vernooij-Dassen et al 2005, Iliffe et al 2009):

- Advancing disease.
- Delays in carrying out diagnostic tests.
- Potential reluctance by doctors to make a diagnosis.
- Family members, or closest others, discouraging healthcare professionals from providing timely diagnosis because of the effect it could have on their relatives or loved ones.

The rationale for providing timely diagnosis to people with dementia is to enable them to have access to information about their condition, decide on treatment options and, importantly, enable future planning, such as advance care directives (Mitchell et al 2013). Due to the nature of disease progression, it is paramount that diagnosis is timely for those who wish to receive it.

Nurses can identify people without a formal diagnosis who may present with symptoms (Page et al 2008) in primary, acute or long-term care settings (Robinson et al 2011). They can also support people to make decisions about whether they wish to receive a diagnosis, as well as provide information to family members or closest others about available treatments and the advantages of disclosure. Nurses have an important part to play in helping people with dementia and their loved ones decide on
their future through advance care planning (Woods and Pratt 2005).

Dementia
The term ‘dementia’ refers to a group of syndromes characterised by progressive cognitive decline and is almost always associated with increasing age. According to Stephan and Brayne (2008), 200 different subtypes of dementia have been defined, with the main types known to be Alzheimer’s disease, vascular dementia and dementia with Lewy bodies. The clinical manifestations of all dementias can vary significantly from person to person but are generally characterised by progressive loss of memory, language deterioration, poor judgement and difficulty in performing practical tasks previously considered easy (Ballard et al 2011). The aetiologies associated with dementia are largely idiopathic and poorly understood (Mitchell 2013).

People with dementia require high levels of care (Ferri et al 2005). Dementia cost the UK economy £23 billion in 2008, greater than the costs of cancer and heart disease combined. With an ageing population, the cost is set to rise by an estimated 20 per cent in the next 15 years (International Longevity Centre-UK (ILC-UK) 2011).

Dementia directly affects 820,000 people in the UK but its effect is global. According to the World Health Organization (2012), 24 million people worldwide had a diagnosis of dementia in 2001, and estimates suggest that by the year 2050 this figure will be 115 million. Dementia is the leading chronic disease contributor to disability and dependence in care, yet some commentators believe these statistics are conservative, because it is estimated that around 40 per cent of people worldwide have undiagnosed dementia (Bamford 2010, ILC-UK 2011, Alzheimer’s Society 2012).

Diagnosis disclosure
Timely diagnosis is potentially a gateway to living well with dementia. Absence of a clear and direct diagnosis means that personal care preferences, pharmacological interventions and appropriate support mechanisms may be more difficult to put in place. As in the UK, there is widespread disparity in disclosure of diagnosis and consequent care of people with dementia across the world (Bamford et al 2004, Downs et al 2006, Georges and Gove 2007, Robinson et al 2011).

Mitchell et al (2013) identified 12 studies in the past seven years on the theme of diagnosis disclosure from the perspective of people with dementia. While a diagnosis had the potential to be devastating, there were positive factors associated with it, which included joining support groups and meeting other people with dementia, having more time to spend on activities that made the person happy, being able to deal with financial affairs and plan future care with health professionals (Mitchell et al 2013). Two previous reviews by Robinson et al (2011) and Bamford et al (2004) support these sentiments.

There is a paucity of statistical evidence about the extent to which people with dementia wish to know their diagnosis before receiving it (Mitchell et al 2012). However, four studies that sought personal opinions about diagnosis from the perspective of those with dementia-like symptoms and who were undiagnosed, found that between 69 per cent and 96 per cent wished to know their diagnosis (Marzanski 2000, Dautzenberg et al 2003, Pinner and Bouman 2003, Elson 2006). These wide-ranging statistics highlight that every diagnostic process is unique and should be tailored to the individual. Nurses can support people with dementia to decide whether they wish to receive the diagnosis.

Family members or closest others and diagnosing dementia
Many people still see dementia not as a medical condition but as a consequence of growing old (Mitchell et al 2012). According to Bond et al (2005), 58 per cent of informal carers, including family members and closest others, surveyed across Europe wrongly identified symptoms of dementia as part of the normal ageing process.

This lack of public awareness has the potential to be detrimental to the person with dementia symptoms. All healthcare providers, especially nurses, are well placed to educate family members about the possibility of dementia and the potential benefits of timely disclosure to the person with dementia, which includes advance planning about future care preferences while the person has capacity (DH 2009). This is especially pertinent given that it is becoming more common for family members to broach the topic of dementia with a health professional before they are formally seen in clinical practice (Iliffe et al 2009).

Family members play an integral role in the person with dementia’s journey and are likely to assume the role of advocate when the condition becomes advanced (DH 2005, 2012). There is increasing support, mainly in the form of groups and assistance with financial care packages, for families of those who have a relative with dementia (National Audit Office 2007). The national dementia strategy (DH 2009) has support for carers as one of its main objectives. Importantly, nurses have a
duty of care not only to patients but also to their families or closest others (Denin et al 2011). Given the clinical manifestations of dementia, it is also likely that as the condition advances, people with dementia will be unable to make complex decisions about their care.

As a result of this, the role of families, or closest others, is likely to change as, along with nurses, they will deliver care based on advance directives made by the person with dementia and what families and healthcare teams agree is in patients’ best interests according to the Mental Capacity Act 2005 and end of life care strategy (DH 2008). It is therefore best practice for nurses to engage with people with dementia as well as their families at the earliest juncture.

There are ethical implications about providing a diagnosis to people with dementia. There are international variations in the opinions of family members and informal carers about whether they believe a diagnosis should be given to their loved ones. The obvious tension between doing no harm and giving people the right to make a decision about whether they wish to receive their diagnosis is an important bioethical debate (Mitchell et al 2013).

A study conducted in Brazil (Shimizu et al 2008) found that only 58 per cent of carers of people with dementia believed the diagnosis should be disclosed. In a similar study in Taiwan, this number was 76 per cent (Lin et al 2005) and in a study in Finland (Laakkonen et al 2008), 97 per cent of carers believed diagnosis should be disclosed to their relative.

A study in Belgium (Bouckaert and van den Bosch 2005) found only 43 per cent of relatives supported disclosure, while in Italy, Pucci et al (2003) found only 39 per cent of relatives favoured disclosure. While the reasons for this global disparity are unclear, these are important considerations for nurses to be aware of before engagement with families of people with dementia. This disparity is perhaps a reflection on the uniqueness of people with dementia as well as the attitudes and feelings of their families.

The multidisciplinary team and rates of dementia disclosure
The role of the multidisciplinary team (MDT) in diagnosis is another variable that should be considered. Internationally, it takes an average of 30 months from initial symptoms before a medical assessment takes place (Vernooy-Dassen et al 2005). In the UK, the process is estimated to take between 18 and 30 months (Iliffe et al 2009). There are many reasons for this. The National Institute for Health and Care Excellence (NICE) (2011a) advises that a comprehensive diagnosis can only be made after thorough investigations, for example, electrocardiogram, thyroid function tests and review of medication.

All of these can take considerable time, but are necessary in guarding against incorrect diagnosis. These tests can rule out other conditions that may have symptoms similar to dementia and that may be treatable, including depression, chest and urinary infections, severe constipation, vitamin and thyroid deficiencies and brain tumours (Iliffe et al 2009). Due to the progressive nature of dementia, any delays in diagnosis are considered detrimental, because they will limit the extent to which future planning can occur (Mitchell et al 2012, 2013).

In the UK, the person with symptoms usually visits a GP in the first instance. After a number of tests, the GP may be able to make a diagnosis of dementia. However, this is not always the case and referral to a neurologist may be appropriate (Iliffe et al 2009). While referral to a neurologist will provide a greater level of certainty, it does extend the diagnostic process considerably.

Naturally, GPs are encouraged to seek the expertise of specialist neurologists, but it has been argued that limited confidence among GPs is an important factor in delaying a timely diagnosis of dementia (Mitchell et al 2012). GPs can call on the services of experienced practice nurses, dementia care advisers or community psychiatric nurses for support in these circumstances (Keady 2008). These specialist practitioners are important to identify early in the diagnostic process because they are likely to be pertinent advocates for people with dementia for the duration of their illness.

In a Dutch study of GPs, van Hout et al (2007) found that only 58 per cent felt confident in making a diagnosis to people with dementia. The barriers to diagnosis included limited knowledge of symptoms and reluctance to disclose. Similar findings were made in a Scottish study of GPs’ knowledge and confidence (Turner et al 2004), however 33 per cent of those surveyed believed that dementia diagnosis should be made in a specialist domain by someone with clinical expertise and experience relating to dementia.

A rural study of GPs in Kansas, US, found that many stated that ‘no one wanted a diagnosis of Alzheimer’s disease’ and those diagnosed were often reluctant to accept the diagnosis (Teel 2004). It was also recognised that the diagnostic process was complex, as a great number of tests were required to rule out other conditions. In a German study, Kaduszkiewicz et al (2008) found little difference in
Implications for practice

A number of benefits are associated with timely diagnosis. However, not all people with symptoms wish to know their diagnosis. Importantly, nurses involved in the diagnostic journey should seek to establish early on whether people wish to know the diagnosis. Nurses are well placed to summarise the benefits of disclosure and support people with dementia and their families to make a decision based on their needs. Timely diagnosis is a relief for some patients because it confirms that they are not ‘going mad’, or being kept in the dark about their condition (Keightley and Mitchell 2004). Timely diagnosis is essential for future planning and Moniz-Cook et al (2006) found that people with dementia who had this were able to manage their condition more effectively than a control group who were not informed of their diagnosis.

Further research identifies the value of early diagnosis in improving quality of life for people with dementia by delaying entry into a care home (Mittelman et al 2007). Gaugler et al (2005) identified a 22 per cent reduction in admission to long-term care facilities through early access to community support services. Banerjee et al (2007) found a 28 per cent reduction in care home admissions after a brief programme of support for family members following disclosure. A reduction in care home admissions is favourable because it allows people with dementia to retain their living space, either by remaining in their own home or moving into shared accommodation, and is financially more sustainable (DH 2009).

NICE (2011b) identifies that certain pharmacological agents should be made available on the NHS for people with dementia. These include donepezil, rivastigmine and galantamine (Mitchell

References


2013). While there is no cure for dementia, these medicines can delay some of the symptoms, or in other words, slow down the disease process (Downs and Bowers 2008). Importantly, any delay in formal diagnosis can delay appropriate pharmacological treatments for people with dementia (Mitchell 2013).

Timely detection in primary care is required to ensure that potentially effective drug regimens can be implemented (Mitchell 2013). Nurses who provide long-term care to people with dementia are well placed to monitor medication efficacy and establish when it diminishes. As a consequence of this, nurses can liaise with MDTs with a view to potentially revising prescriptions or withdrawing those deemed no longer effective. This saves the NHS money on medications that are no longer therapeutic and ensures that people with dementia receive the most therapeutic medicines.

Timely diagnosis also empowers people with dementia to make important decisions about their future care. It enables them to contemplate legal and financial provisions, which might include making a will or appointing a solicitor to manage their affairs (Brooker 2007, Milne 2010). Importantly, people with dementia can also make ‘advance decisions’ or ‘living wills’, which detail treatment preferences or situations where they wish to refuse treatment if they lose capacity in the future (Woods and Pratt 2005). Nurses have an important role to play in development and facilitation of advance care plans (Dening et al 2011) and making people with dementia and their families aware of such plans. This enables people with dementia to communicate their preferred treatment options now and in the future, even once their capacity diminishes (Dening et al 2011).

Conclusion

The number of people with dementia without a diagnosis has been identified as an area of concern in the UK in recent years. There are many complex reasons for this, which include personal preference not to receive a diagnosis, families’ failure to recognise symptoms, the potential of causing people with dementia distress and primary care teams’ reduced level of confidence in delivering a diagnosis. Despite these challenges, nurses are well placed to provide advice, support and practical care for those on their diagnostic journey and subsequently through into longer-term care. Nurses can illuminate the potential benefits of receiving a diagnosis as well as supporting family members through their own personal journeys.