

Policy analysis on dementia care

[Health & Medicine](#), [Disease](#)



Abstract

The policy ‘Improving Care for People with Dementia’ aims to increase diagnosis of dementia, improve health and care services in hospitals, care homes and communities, create dementia-friendly communities and widen research on dementia care. This brief aims to analyse only the aspect of improving health and care services in communities and the patients’ homes and relate this to the district nurse’s role of bringing care to the patient’s home and community. With an ageing population, the London Borough of Hackney, and the rest of the UK, is experiencing increased incidence of dementia. The costs associated with dementia care are approximately ? 23bn annually in the UK.

As a district nurse, this policy is important since it seeks to improve the care received by patients in community settings or their own homes. My caseload demonstrates a disproportionate number of patients suffering from dementia and the resources channelled to their care. Dementia is a chronic and complex condition and requires interventions from different health and social care professionals. However, informal carers bear most of the burden of caring. As a district nurse, I have to address the patients and the carers’ needs. Patients need to receive interventions to improve their nutrition, health and wellbeing. Carers need to receive training on how to feed their patients, ease their anxiety, regulate their sleeping habits or improve their mobility and independence. Meeting all these needs require additional training and collaboration between the district nurses and other health and social care professionals.

The Department of Health and the Royal College of Nursing have acknowledged the district nurses' role in meeting the needs of patients with dementia in hospital settings. These nurses are tasked to prevent admission of patients and promote positive experiences for families during end of life care. However, the politics and economic context of this policy could all influence the care received by the patients. Ethics also play a role in delivery of care. The state's apparent withdrawal of minimum service and delegating most of the task to home care could have ethical implications. Safeguards to quality care most commonly seen in wards or hospitals are missing in home care. This might do more harm for the patient than good. However, district nurses still have to weigh if choosing to provide care at home would be more beneficial for the patient or otherwise. Finally, this brief shows that community care for patients with dementia is possible if district nurse teams are dedicated and the workforce increased to respond to the increasing workload.

Introduction

The Department of Health Public Health Nursing (2013) has recognised that care for patients with long-term conditions often continue in their own communities and in the people's homes. This type of care would require sustained relationships with district nurses (DN), who are responsible for managing the patient's healthcare conditions. This brief aims to critically analyse the policy Improving Care for People with Dementia (Department of Health, 2013) and will relate this with the Department of Health Public Health Nursing's (2013) Care in Local communities- District Nurse Vision and Model.

The Department of Health Public Health Nursing (2013) has acknowledged that this new vision is a response to the growing needs of the ageing population in the UK. Specifically, it has recognised the growing incidence of dementia amongst the elderly population and this vision sets out the contribution of DNs and other healthcare teams in meeting the challenge of dementia.

The first part of this brief justifies the choice of this policy and the focus on dementia care. A community in Hackney is chosen in this brief to represent my nursing caseloads of dementia. The second part discusses political, economic and philosophical context of the policy. The third part critically appraises the ethical and moral implications of this policy for practice.

Policy on Dementia Care and the Community of Hackney

With an ageing population, the London Borough of Hackney, like the rest of the UK, is faced with a rising incidence of the long-term conditions associated with old age (Office for National Statistics, 2013). According to the Alzheimer's Research UK (2013), more than 820, 000 elderly individuals are affected by dementia. The rate of dementia in Hackney is four times higher than that of the general population's rate (Public Health England, 2013). In 2010, approximately 1, 350 elderly people were living with dementia in Hackney (NHS, 2012). This policy aims to increase diagnosis rate, improve health and care services in hospitals, care homes, communities and homes, create dementia-friendly communities and widen research on dementia care. This brief will only focus on improving health and

care services in communities and homes and relate these to the DNs role in providing care to patients in their own communities and homes.

Implications of the Policy on Current Practice

The policy on dementia care has an important implication in my practice as a district nurse. Providing holistic interventions to improve the quality of care in community settings require collaborative efforts of health and social care professionals (National Collaborating Centre for Mental Health, 2007). As a district nurse, I take the lead in provision of healthcare in community settings. On reflection, patients with dementia have complex needs that require collaborative care from nurses, physical and occupational therapists, dieticians, social care workers and other healthcare professionals. My role extends from planning care to coordinating care with other professionals.

The King's Fund (2012) explains that multidisciplinary teams are needed to provide quality care to patients. However, the quality of care could be affected if there are fewer nurses caring for patients. I observed that the number of registered nurses in my practice is declining. This observation is similar in a survey conducted by the Royal College of Nursing (2011), which reported that almost 70% of district nurse respondents claimed that registered nurses in their staff have dropped out. In my current caseload, a third of my patients in our team suffer from dementia. The incidence of dementia in Hackney is four times higher compared to the UK's average (Public Health England, 2013). However, due to the nature of the condition, the care of this group of patients requires a disproportionate amount of time and resources. One of the duties of DNs in addressing the policy on dementia

care is to ensure that carers also receive appropriate support. Carers have the right to have their needs assessed under the Carers and Disabled Children Act 2000 (UK Legislation, 2000). In my experience, CBT has been shown to be effective not only in reducing anxiety in my patients but also depression in the carers. It has been shown that joining support groups has been associated with reduced incidence of depression (NICE, 2006).

Implications of the Policy on Future Practice

With the increasing focus on community care, there is a need to strengthen the district nurse workforce. Based on my experiences and observation, the quality of care could be compromised due to the decreasing number of DNs (Queen's Nursing Institute, 2010). There is increased pressure to provide quality care at the least cost and with reduced number of nurses (Queen's Nursing Institute, 2010). Establishing a therapeutic relationship is difficult when the continuous decline of healthcare workforce in the community is not addressed. Sheehan et al. (2009) argue that a positive relationship between healthcare professionals and the patient is needed in order to make healthcare decisions that would dictate the future of the patient. Based on these observations, the policy on dementia care would require additional workforce of registered nurses who would be willing to work in community settings. At present, the issue of sustainability of the DN workforce in meeting the present and future demands of elderly patients has been raised (Royal College of Nursing, 2013, 2011). Unless the issue of reduced workforce is not addressed, meeting the demands of the dementia policy would continue to be difficult.

The policy would also require additional education and training for nurses. The Royal College of Nursing (2013) has acknowledged that the present DN workforce is highly qualified. Many have met the qualifications of nurse prescriber or district nurse while the rest of the staff either have completed qualifications for nursing first or second level registration or at least hold a nursing degree. However, the Royal College of Nursing (2013) also notes that the workforce number is still low. A small workforce could not adequately meet these needs. Further, the ageing population in the UK would mean that the NHS would continue to see a rise in the incidence of dementia in the succeeding years.

The issue of recording performance data is also raised with the recent policy on dementia care. This would be a challenge since a community or a home does not present any safeguards commonly found in a controlled environment such as wards in hospital settings (Royal College of Nursing, 2013). There is also a need for DNs to be trained on how to give education and training to caregivers. In a systematic review conducted by Zabalegui et al. (2014), suggest that the quality of care of patients with dementia living at home could be improved if caregivers receive sufficient education and training from healthcare providers.

Political, Economic and Philosophical Context

The Alzheimer's society (2014) states that in the UK, approximately £23 billion is spent annually to manage patients with dementia. However, the same organisation is quick to observe that a large portion of this cost is borne by carers of the patient rather than social care services or the NHS. To date, there is only one study (Alzheimer's UK, 2007) that investigated the

cost of managing patients with dementia in community settings. The report shows that in 2007, the cost of managing one patient with mild dementia within one year in a community setting amounts to ? 14, 540. For an individual with moderate dementia, the annual cost is ? 20, 355. This increases to ? 28, 527 for a patient with severe dementia. If a patient is sent to a care home, the annual cost of managing the condition amounts to ? 31, 263. It should be noted that all these costs were calculated almost 7 years ago. The individual cost of treatment is now higher.

The same survey also shows that majority of the costs of dementia care is channelled to the carers. However, these costs do not account for the informal carers. Alzheimer's UK (2007) estimates that the number of hours informal carers devote to caring run up to 1. 5bn hours each year. This translates to ? 12bn in cost, which is higher than the combined health and social care cost for dementia. Patients with severe dementia living in their homes or communities need at least 46 hours of paid carer support within a week (Alzheimer's UK, 2007). However, the changing dynamics of families, with children living far from their parents or loss of spouse due to divorce or death could limit the pool of family carers. This issue could all influence the impact of the service provided by informal carers of dementia.

The ageing population of the UK (Office for National Statistics, 2013) could further drive up the cost of caring for patients with dementia. The policy on dementia care increasingly depends on homes and communities to support the care of patients with dementia. Since many informal carers manage patients with dementia, the burden of caring is now channelled to the

patient's family. The main stakeholders then for this policy include informal carers, patients, DN staff and multidisciplinary team. This increasing reliance on home care and management could even be viewed as a strategy of the NHS to reduce the cost of caring for patients with dementia. There is also a concern on whether the quality of care is maintained at home, especially with fewer DNs supervising the care at home.

Apart from the economic cost, politics could also influence DN practice. As with other policies, the policy on dementia (Department of Health, 2013) bring care close to home and care at home. These gradual changes are projected to empower patients, lower costs of healthcare while empowering communities to take care of their own health (Department of Health, 2013). The withdrawal of the state in providing minimum services for patients with dementia in favour of care at home should be evaluated on whether this would cause harm to the patient. If care at home would be possible with supportive carers, my role as a DN would focus on coordinating care with other healthcare professionals. However, if the patient does not receive sufficient support, the Mental Health Act 2007 (UK Legislation, 2007) mandates the appointment of a carer for the patient. The consequences of the political context of moving care closer to home for patients with dementia would be felt in the succeeding years. On reflection, making this policy work would require DNs to provide adequate support to the informal carers.

The philosophical underpinning of this policy focuses on tackling health inequalities. Social determinants of health (NHS, 2012) have long known to

influence the health outcomes of many individuals. In the London Borough of Hackney, incidence of dementia is higher amongst the older black elderly compared to the general white population (Office for National Statistics, 2013; Public Health England, 2013). Yaffe et al. (2013) argue that genetics do not account entirely on the disparity of incidence between black and white older populations in the UK. Instead, Yaffe et al. (2013) maintain that socioeconomic differences appear to have a greater influence on the higher incidence of dementia amongst black older people. Related risk factors for dementia such as poorer health, less education and literacy are higher in the black elderly and might account for the variation in dementia incidence. A number of earlier studies (Haas et al., 2012; Thorpe et al., 2011) have pointed out the relationship between socioeconomic status and cognitive outcomes. The dementia policy not only brings care closer to home but also addresses socio-economic disparities of patients with dementia by allowing DNs to provide care in home settings. However, this is still challenging since carers and family members would provide care on a daily basis. The limited financial capacities of families with lower socio-economic status could have an effect on the nutritional status and physical health of the patients (Adelman et al., 2009). It has been stressed that poor nutrition and health could increase the risk of cognitive decline (Adelman et al., 2011).

Ethical and Moral Implications of the Dementia Policy for Practice

Approaches to ethics include the Deontological approach, Justice, Virtue and Consequentialism. Fry (2010) explain that in deontology, individuals should perform an action because it is their duty to do so regardless of the

consequences of the action. The Dementia Policy in the UK is underpinned by ethical approaches. Using deontology, it is moral for nurses and carers to provide care for patients with dementia. In rule-deontology, decisions regarding the care of patients become moral when these follow the rules. Fry (2010) emphasise that the actions of individuals following deontology is usually predictable since it follows set of rules.

A second approach to ethics called the Results of Actions (Fry, 2010) is opposite to deontology. In this ethics approach, an action becomes moral when its consequences produce more advantages for the patient than disadvantages. The third approach to ethics or the virtue approach states that there is an ideal that should be pursued by individuals in order to develop their full potential (Jackson, 2013). This approach is more encompassing than the deontological approach since it seeks to make a person moral by acquiring virtues. A review of the policy reveals that the virtue approach is followed since it seeks to provide holistic care to the patients. The policy emphasises providing psychological, social and emotional support not only to patients but also to their carers.

Meanwhile, Beauchamp and Childress (2001) have set out four principles of ethics. These are autonomy, non-maleficence, beneficence and justice. The Nursing and Midwifery Council's (NMC, 2008) code of conduct has stressed that patient autonomy should always be observed in all healthcare settings. A review of the dementia policy reveals that allowing patient's to be cared in their home settings would likely increase patient autonomy.

Patients in the early stages of dementia or those with moderate forms of the condition could experience cognitive impairments but still have the capacity to decide for themselves (Department of Health, 2009). The Mental Capacity Act 2005 (UK Legislation, 2005) states that only when patients suffer significant cognitive impairments should representatives of the patients be allowed to make decisions in behalf of the patient. Since the policy focuses on patient-centred care even in home settings, patients or their family members are allowed to decide on the best treatment or management for the patients. District nurses are encouraged in the policy to always seek for the patient's interest. The emphasis of the policy on allowing patients to decide about their care is consistent with the ethical principle of autonomy.

It is also important that nurses should first do no harm to the patients as embodied in the ethics principle of non-maleficence (Beauchamp and Childress, 2001). The policy supports this principle since DNs are available to provide support and lead the care of patients in home settings. However, there are several barriers in implementing the full policy. Although the policy specifies that DNs should rally the support of patients in home settings, there is the growing concern that the standards of care seen in hospital settings might not be transferred in home settings (King's Fund, 2012). For instance, DNs could not regularly supervise carers on a daily basis on how they provide care to individuals with dementia. These patients need to receive sufficient nutrition, engage in exercises that increase their mobility or regularly receive pharmacologic medications for their conditions (Casartelli et al., 2013; Hopper et al., 2013; Cole, 2012; Bryon et al., 2012). It

would be difficult to determine on a regular basis if all these tasks are carried out according to standards if patients are cared in their own homes.

In a recent King's Fund (2013) report, the quality of care received by patients from their nurses is highlighted. This report observes that not all nurses are compassionate to their patients and often, basic care such as feeding or giving water to the patients are often neglected. While this report was based on a study in only one hospital setting, the results are important since it showed that basic care might not be observed. In contrast, DNs would only visit the patients in their homes and would not be around to provide long hours of care. If patients receive poor quality care, this could result to poorer health outcomes and faster deterioration of the patient. The ethics principle of non-maleficence might not be observed if the volume of DN staff in the community remains low. There has been an association of high volume of work and low staffing amongst nurses with poor quality care (King's Fund, 2013, 2012).

The policy also observes the principle of beneficence since its primary outcome is to improve the quality of care received by older patients with dementia in their own homes. Although providing care in home settings would drastically reduce healthcare costs for dementia care, it is still unclear if this would benefit the family more. The cost of informal carers remains to be high, and yet is often discounted when approximating the cost of care for dementia (Alzheimer's Society, 2014). This policy might put undue burden on families who lack the capacity to provide care for patients in advanced stages of dementia on a 24 hours basis (Alzheimer's Society, 2014). Despite

this observation, the policy is beneficial to patients with moderate dementia. A home setting might provide them with the stability and familiarity that is absent in hospital settings (Sheehan et al., 2009). It has been shown that when patients are admitted in hospital settings, they often manifest aggressive behaviour that is suggested to be a response to the changes in environment (Sheehan et al., 2009). The ethics principle of justice is also observed since the policy requires all patients, regardless of race or gender and socio-economic status, to receive equitable healthcare (Department of Health, 2013).

On reflection, the moral implications of the policy might come into conflict with the state's increasing reliance on informal carers or family members to provide care for patients with dementia. The issue lies on whether it is moral to delegate most of the care to informal carers who might also need additional support when caring for patients with progressive chronic conditions. The National Collaborating Centre for Mental Health (2007) stresses that informal carers also need support to help them manage depression, stress or burnout from providing care to patients who would never recover from their condition. While the NHS continue to practice innovation in delivering care, an evaluation on whether there are enough resources to implement the innovation should be made.

Conclusion

In conclusion, the recent policy on dementia in the UK sets the direction of care in community or home settings. District nurses are in the position of following this direction since they lead patient care at home and in the

community. However, this brief highlights some issues that should be addressed. These include the decreasing workforce of DN and their staff and their need for additional training and education. The political and economic context influencing the dementia policy should also be taken into account. Finally, this brief illustrates the role of DNs in providing quality care to patients in community and home settings. They could lobby for the patient's rights and coordinate collaborative care between healthcare professionals and those involved in social care.

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