Dementia and stigma: a review of the literature on the reality of living with dementia

Alison Kilduff examines the literature on the effects of stigma and ageism in dementia care

Introduction
With the numbers of individuals diagnosed with dementia-related disorders expected to significantly rise in the next few decades from 670,000 to approximately 1,340,000 (Department of Health, 2009), it is imperative that health and social care professionals are equipped with knowledge, skills and understanding to meet the needs of people living with dementia.

Individuals living with a diagnosis of dementia are significant users of mainstream health and social care services. At any one time in an acute hospital, one third of the beds will be occupied by someone living with dementia.

Furthermore, a report by the Care Quality Commission (CQC, 2013) highlighted that people living with dementia are far more likely to go to hospital with avoidable conditions, such as urinary infections, dehydration and pressure sores than their peers.

Once admitted, they will stay much longer in hospital, be more likely to be readmitted and are much more likely to die in hospital than similar people without dementia.

Common themes in the evidence heard in the inquiry consisted of patient’s call bells being unanswered, patients left lying in their own urine and faeces for long periods of time, and food and drink being left for patients out of their reach.

Many of these events related to the care of the most vulnerable people in our society, older people and people who were diagnosed with dementia.

In 2007 dementia was declared a national priority, which led to intensive consultation and development of the National Dementia Strategy (Department of Health, 2009).

Principles of the strategy included improving awareness and understanding of dementia nationally, the provision of early specialist diagnosis, effectively managing the overuse and reliance on antipsychotics in coping with challenging behaviour and the implementation of supportive, collaborative relationship with individuals and carers, to enable positive physical and psychological wellbeing from diagnosis through to end of life care.

It therefore seems timely to consider
Dementia special

why, five years after the introduction of the National Dementia Strategy (Department of Health, 2009) there is still evidence to suggest that individuals are not living well with dementia (Alzheimer’s Society, 2012).

This paper offers a short review of the evidence related to how stigma may be one aspect that can impact on the individual’s ability to ‘live well’ with the diagnosis.

The Alzheimer’s Society (2012) suggest that misunderstanding and stigma can elicit a particular response related specifically to the diagnosis of dementia. Furthermore, they propose that this can culminate in infringements being made on an individual’s human rights where rights to privacy, dignity, liberty, choice and decision making can be overridden.

Ageism and stigma

It has long been acknowledged that ageist attitudes can have a detrimental effect on care experiences in older adult care (Audit Commission, 2004; Clarke, 2005; Royal College of Psychiatrists, 2009) and that this form of discrimination can lead to older people being perceived as somehow inferior to other younger adults.

Collier (2005) cited a concerning example of ageism from the Age Concern report Turning Your Back On Us (Gilchrist, 1999), which showed that one in ten GPs declined to refer older people to secondary care because they have had a ‘good innings’.

However, ageism and age discrimination alone cannot account for the stigma, marginalisation, lack of choice and non-involvement in decision-making that the growing number of younger people being diagnosed with dementia experience and consistently report (Alzheimer’s Society, 2008).

It is hypothesised that even the term ‘dementia’ may elicit a particular response related to stigmatising and stereotypical views in health and social care professionals and also the general public.

Goffman (1963: 12), in his seminal work Stigma: Notes on the Management of a Spoiled Identity, suggested stigma is an attribute and significantly affects the person’s sense of self and perception by others. He defines stigma as being ‘deeply discrediting... he is thus reduced in our minds from a whole and usual person to a tainted, discounted one’.

Kitwood’s views on stigma

Kitwood (1979) defines personhood as a ‘status or standing bestowed upon one human being by others, in the context of a social relationship and social being’ (Kitwood 1979: 8).

Kitwood’s early work asserted that harm to an individual’s psychological wellbeing could be done, often unintentionally, by actions and words of people caring for individuals living with dementia, thereby reducing them to a lesser person.

Kitwood (1979) used the term ‘malignant social psychology’ to describe this process. This concept is defined as devaluing, depersonalising and diminishing the person with dementia, which in turn reduces them to less than a person. As a consequence, their rights and needs are not considered.

Kitwood and colleagues in Bradford observed and categorised episodes where people with dementia were stigmatised, invalidated or ignored. Kitwood suggests that it is rarely carried out with malicious intent or consciousness; the ‘malignancy’ is that it becomes the norm and unnoticed.

The dementia becomes the individual’s determining characteristic and all other aspects of their individuality and personality are overlooked or lost.

Although Kitwood is widely acknowledged for challenging the traditional medical paradigm that has existed in dementia care since it was acknowledged as an illness, Kitwood’s work has been criticised for lacking empiricism, in that is an unproven theory (Innes, 2009).

Addressing stigma related to the diagnosis of dementia may need to be considered as part of the solution for health and social care, if the problems that were evident at Mid Staffordshire are to be addressed.

This would prevent stigma perversing the culture of care in hospital settings and ensuring that all care was person-centred and focused on compassion and understanding.

Dementia and stigma

Dementia is the most feared consequence of ageing (Alzheimer’s Society, 2008), although Brooker (2007) suggests that, because of its association with mental ill health, people living with dementia suffer more prejudice than any other illness.

Gillon (2003), citing Kant, proposes that this may be because of a perceived lack of rationality, which is viewed as a part of personhood and assumed not to be present in people living with dementia.

It is suggested that the extent of unequal and unjust treatment is evident in a range of aspects related to the care and treatment of dementia, including service provision, resource allocation, research funding, media coverage, policy priorities, professional training, status and pay of dementia care workers (Brooker, 2007).

Two of the reviewed studies attempted to include the voices of ‘seldom heard groups’ (Alzheimer’s Society, 2008) and ‘hard to reach groups’ (Katz et al, 2013) in an attempt to increase the diversity and value of their studies.

In relation to first generation migrants, who are now reaching an age when the risk of developing dementia is increased, there is a further increased risk because of the prevalence of hypertension and diabetes, which can be undetected, or untreated (Parker and Philip, 2004).

There are concerns that stigma and discrimination for individuals living with dementia extends further for groups who are already marginalised and excluded, which can lead to a reluctance to seek help and support from services.

Katz et al’s (2013) study noted that while many of the participants in the study coped with a range of complex needs, they rarely expressed dissatisfaction with the care they were receiving from services.

Katz et al (2013) suggested that as the majority of this cohort had grown up during or after the Second World War, before the development of the welfare state, some of the cohort had previously experienced worry and/or poverty in their life history and were grateful for any help they received.

Bawling (2001) suggested that this was a law of ‘inverse satisfaction’ wherein older people may be inclined to agree with the ‘fair innings’ principle in that they are ‘lucky’ in

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comparison to their parents.

Bowling (2001) also comments that researchers could be more robust in the design of the studies, in that if satisfaction questionnaires were more open ended and in depth, they could elicit a more transparent view of older people's real experiences in health and social care and could yield higher levels of criticism.

This measure could be enabling for vulnerable individuals and those living with dementia and would prevent them becoming unheard and invisible.

Early diagnosis, early onset dementia and stigma

While the link between ageing and dementia has been recognised as being linked to discriminatory practice, there is growing evidence that stigma and discrimination are evident in the care and attitudes that younger people experience when they are diagnosed and living with dementia.

Numerous studies have highlighted several issues that significantly impacted on younger individuals living with dementia, particularly surrounding a timely diagnosis (Beeston, 2010; Alzheimer’s Society, 2008; 2012; Pratt and Wilkinson, 2001).

When reviewing the literature, there was a consensus that early diagnosis was a positive initiative and it enabled choice and decision making for the person living with dementia, which was identified as a prerequisite for ‘living well’. This was particularly apparent in some of the narrative accounts of people ‘living well’. This was particularly apparent in some of the narrative accounts of people ‘living well’. This was particularly apparent in some of the narrative accounts of people ‘living well’. This was particularly apparent in some of the narrative accounts of people ‘living well’. This was particularly apparent in some of the narrative accounts of people ‘living well’. This was particularly apparent in some of the narrative accounts of people ‘living well’.

Therapeutic nihilism — stigma or ignorance?

As the traditional dominant medical approach in dementia care has been challenged in the past 25 years and has moved to a more person-centred model, particularly following on from Kitwood’s early work in the 1980s and 1990s emphasising a psycho social approach, contemporary mental health services for people of working age are primarily concerned with a recovery model (Shepherd et al, 2008).

The recovery framework’s guiding principle is hope, with a belief that it is possible for someone to regain a meaningful life after a diagnosis of a mental health problem.

In relation to therapeutic nihilism, Adams (2010: 627), asserts: ‘underlying therapeutic nihilism is the view that there can be no recovery for people with dementia’.

Therapeutic nihilism stems from the belief that there is no recognised cure or treatment for an illness and is based on attitudes that the disclosure of this truth may be damaging and destroy a person’s hope for the future.


This pervasive negative theme is also acknowledged in Katsuno’s study (2005) where participants clearly identified that widely emphasised in government policies in both countries, neither group were proactive in diagnosing dementia as it was difficult news to give and had ‘profound implications’, (Moore and Cahill, 2013: 79).

There is currently no cure for dementia and although there are some recognised treatments that are licensed for Alzheimer’s disease, which help some people cope with the symptoms, they have not been as successful in halting the progression of the illness as it was hoped (Alzheimer’s Society, 2008).

The author Terry Pratchett, who was diagnosed with dementia, wrote the foreword of the Alzheimer’s Society’s Out of the Shadows (2008) and illuminated this issue when he suggested that a commonly prescribed anti-dementia medication he uses is: ‘not a cure, but acts as a line of sandbags against a rising tide of the unknowing’ (Alzheimer’s Society, 2008).

Unlike many other long-term conditions, dementia has continued to have negative and unhelpful representation in our culture throughout history.

Kitwood (1997) described traditional care of people with dementia as ‘warehousing’, in that people with dementia were kept and housed out of sight, and within this understanding the aim of nursing people with dementia was concerned with physical needs and containment.

Even the term dementia is wholly negative in its meaning. It is derived from Latin and its literal translation is to de (to depart) from the mens (mind). The language used to describe dementia is pessimistic.
people living with dementia felt they were a ‘lesser person’ and feared losing their autonomy.

In our society, rationality and cognition are highly valued (Kitwood, 1979a) and as individuals living with dementia are deemed to have lost rationality, along with many people diagnosed with a range of mental health problems, they can become the focus of unwarranted attention.

Last year in the media there was a debate regarding major supermarkets selling Halloween costumes based on ‘mental patients’. One costume, on sale nationally, was described as: ‘Comprising a torn bloodstained shirt, bloodstained plastic meat cleaver and gory face mask, it’s a terrifying Halloween option’ (The Guardian, 2013).

This gives a clear example of stigma and discrimination. It would be highly unlikely, due to public outrage, that a chemotherapy cap, used to cool the scalp while a person undergoes chemotherapy, would be used as part of a ‘terrifying Halloween option’ for a fancy dress costume.

The abounding stereotypes associated with mental ill health of irrationality and madness, along with myths and stereotypes associated with older age of senility, dependency and decline can have a ‘double whammy’ effect with regards to the care of older people (Robb et al, 2003).

The media’s influence on society’s perception of dementia is significant and this undoubtedly impacts on healthcare professionals’ views and perceptions, as we are all members of society. As media attention relating to dementia tends to focus on the later stages of the illness, this can become society’s perception of the entire process from diagnosis to end of life.

**Conclusion**

The studies that also explored quality of life indicated that individuals living with dementia were able to enjoy a high quality of life for many years when the right type of care and support was available to them (Alzheimer’s Society, 2012; Katsuno, 2005; Katz et al, 2013).

It is clear that defining people living with dementia as one homogenous group is problematic and leads to stigma and unhelpful perceptions. However, the diagnosis of dementia only adds to the stigma already faced by the individual if they are an older person, increasing their lack of status in treatment and care in which they are neither valued nor respected.

Many years after the notion of malignant social psychology was proposed by Kitwood (1997), evidence continues to demonstrate that individuals living with dementia receive inequitable and unacceptable care that devalues their personhood and sense of self.

This short review has raised a number of ethical complexities while exploring concepts related to stigma and unjust care and treatment of individuals living with a diagnosis of dementia.

Timulak (2008) suggests that, in order to make valued decisions regarding care, there needs to be an acceptable framework in which decisions can be formulated and checked.

The most influential ethical model in healthcare was proposed by Beauchamp and Childress (1994), which advocates principles of autonomy, beneficence, non-maleficence and justice. The model has been developed with a deontological approach, based on the work of Immanuel Kant (1724-1804) and places principles and duties above consequences.

Autonomy is a key concept of Kantian thinking because Kant believed that without freedom people are unable to make rational and moral decisions (Wilmot, 1997). Kant believed that people should always be treated as ends, not means.

The literature reviewed also suggested that inequalities and poor care experienced by people living with dementia is not only influenced by discriminatory attitudes towards age alone, but is specifically related to stigma attached simply to the diagnosis of dementia and would suggest that the diagnosis of dementia could be ‘tainted’ (Goffman, 1963) by stigma.

The studies involving those living with early onset dementia highlighted this issue very clearly. The moral issue regarding diagnosis disclosure emanates from basic ethical principles of autonomy and beneficence (Beauchamp and Childress, 1994). Autonomy is concerned with respecting the rights of an adult to make decisions concerning their life.

However, if disclosing a diagnosis of dementia could be considered to cause harm to that person, then the principle of non-maleficence, not causing harm intentionally, could be justified.

Concerns about catastrophic reactions including suicidal thoughts and depression are widespread according to Pinner and Bouman (2003), despite there being little evidence for this assertion.

In Moore and Cahill’s (2012) study, GPs stated they feared the ‘profound consequences’ of early diagnosis and wanted to protect their patients from the harsh reality of being diagnosed with dementia.

In contrast, all the evidence in the studies reviewed suggested that early or timely diagnosis was beneficial, even though it was often initially distressing to individuals and families, because it gave them time to adjust and helped them plan for the future.

The introduction of the Mental Capacity Act (2005) has been clear in its position that health professionals must presume competence unless there is clear evidence to the contrary. It would therefore follow that all patients have a right to know their diagnosis, unless they specifically stated they did not wish to do so.

The patients’ ‘right to know’ campaign has gained more ground in healthcare in recent years but in dementia care, compared to cancer or other long-term conditions, there is still evidence of paternalistic attitudes that can impact significantly on choice and decision making in the short and longer term.

Professionals’ attitudes towards dementia appeared to significantly affect ‘living well’, particularly in relation to a timely diagnosis and the adjustment process (Moore and Cahill, 2013; Pratt and Wilkinson, 2001; Alzheimer’s Society, 2010).

The concept of therapeutic nihilism suggests that many professional groups believe there is no hope of a meaningful life after diagnosis, a view that is clearly not held by people living with a diagnosis of dementia who participated in the studies by Katsuno (2005), Katz et al (2013), Pratt and Wilkinson (2001), Moyle et al (2005) and numerous

“Early or timely diagnosis is beneficial, even though it is often initially distressing for everyone.”
Alzheimer’s Society studies in 2008, 2010 and 2012. The government has set out key measures to ensure that the confidence of the general public is rebuilt including criminal prosecutions, under a new criminal offence, of wilful neglect and a legal requirement of ‘candour’, both direct recommendations from the Francis report (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013).

According to the Francis report, candour, openness and transparency are central principles in a culture that puts its patients at the heart of its care, and ten recommendations have been made regarding candour, openness and transparency being made a statutory duty (recommendations 173-183).

Candour relates to professionals speaking out about poor care that is being delivered and also about the prevention of poor care. The Francis report has also recommended that poor practices should be part of a new duty of candour that would be legally enforceable and ensure staff do not conceal or obstruct investigations or concerns.

The Royal College of Nursing (2013), in its response to the Francis report, states that poor care, unacceptable behaviours and attitudes are brought about by ‘burnout’ of staff facing constant changes, staffing shortages and the continuous pressure of care giving.

The Royal College of Nursing suggests that by legally enforcing a requirement on staff to disclose information on acts or omissions in care, the measure could be counter productive and lead to a greater culture of fear instead of increasing openness and transparency.

The NHS Institute for Innovation and Improvement (2012), in partnership with the Dementia Action Alliance group, launched a call to action to ensure that individuals living with dementia receive safe, respectful, compassionate care. The call to action committed that every hospital in England would become a dementia friendly hospital and that dementia care would be a key priority for the NHS.

It will be important for health and social care providers to consider the impact therapeutic nihilism may have within their own organisation and identify objectives related to skills, knowledge and attitudes of the workforce that could enable them towards becoming a ‘dementia friendly’ organisation.

Overall, it is imperative that we respond to the individual needs of people living with dementia in a caring, compassionate manner, accepting the gradual cognitive decline — but remembering their rights and appreciating their humanity. MHN

References