

# ETHICAL PERSPECTIVE

## Dementia: stigma and its effects

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## **Practice Points**

- Clinicians should be aware of and resist the tendency to diminish, devalue and socially exclude people living with a dementia.
- The avoidance of people who are 'not like me', namely old and mentally slow, can result in neglect, lack of kindness and social exclusion.
- People with dementia should be supported remain involved in society and to express their thoughts, feelings and views.
- Family and professional carers of people with dementia are valuable individuals who have voices which should be heard and respected.
- Although there is no cure for dementia in most instances, there is much which can be done to influence how people live with it by informed, intelligent good practice.
- Services designed to care for (older) people living with multiple physical and mental disorders including dementia, will serve others well too.
- The Nuffield Council ethical framework for dementia can be used to inform ethical decision-making.

## **Key words**

Dementia; discrimination; ethics; social exclusion; information; personhood; policy; research; service design; stigma.

## **Summary**

In this article we reflect on stigma and the evidence about its effect on the care of people and families living with a dementia. We argue that it distorts services at all levels from people making the decision about seeking help, through those commissioning, designing and providing services, to politicians deciding about priorities and resources. We conclude that ethical non-stigmatising care focuses on personhood and relational aspects of care, and that work to reduce stigma is needed in four main areas: policy, research, information/ education, and service design/ delivery. Dementia is not something that affects other people – it will impact on many of us as we grow older. People living with a dementia must be heard and respected.

In this article we look at some of the literature on stigma and dementia. We reflect on what we understand by stigma and the evidence regarding its influence on people and families living with a dementia and the services provided for them.

### **What do we know about stigma and dementia?**

Whilst there may be broad agreement on what stigma means [1], it is a concept which has been defined in a number of ways and lacks an agreed operational definition: some authors regard it as synonymous with negative opinions [2]. Others have operationalised it in terms of social distance [3], but then concluded that an operational definition needs to include additional measures which draw on other aspects of stigma. A consensus statement [4] included the following under definition:

*'Stigma results from a process whereby certain individuals and groups are unjustifiably rendered shameful, excluded and discriminated against.'* (page 672)

An alternative definition of stigma was used by the Alzheimer's Society:

*'having some form of mark or sign that denotes disgrace or discredit'.* [5]

Stigma has been seen as including three aspects, namely stereotypes, prejudice and discrimination. Stereotypes describe collective judgements about groups of people eg people with dementia; prejudice refers to emotional reactions to a stereotyped person; and discrimination refers to behaviours which are associated with prejudice, including avoidance, coercion and segregation [6]. Werner and Givon interviewed family physicians in Israel and found them to score highly on avoidance (eg reluctance to socialise with a person living with a dementia) and coercion (eg reporting that they would compel the person with a dementia to take drug treatments). They found anger-fear and pity were associated with tendency to discriminate: their paper is an example of one method of investigating stigma, in this case by operationalising discriminatory behaviour. It is also an example of evidence of stigma in healthcare professionals. Another factor in stigma is power differential, which can be regarded as an essential component of stigma [7].

A study of stigma in immigrant Chinese and Vietnamese carers used a different approach: stigma was operationalized using five evidential themes: negative labels eg 'crazy'; 'discrediting stereotypes' eg second childhood; 'negative emotional and social responses'; 'loss of status or discrimination'; and other [7].

Milne argues that people with dementia have to live with the combined impact of the dementia illness plus negative responses to the diagnosis and the symptoms of dementia (which includes the use of negative language), together with 'self-stigmatisation'; and that relatives are subject to 'secondary stigma' [8]. Milne also notes that age discrimination is an additional factor since dementia is an illness of later life, and that age discrimination accentuates the role of stigma. This has been called 'double jeopardy' [9].

Milne's secondary stigma has been called 'stigma by association' [10, 11] or 'courtesy stigma', as Goffman described it as stigma 'courtesy' of a link with people who are subject to stigma [7] – we might argue that this stigma extends to staff working in dementia services as well as the families of people with a dementia. Secondary stigma influences how staff working in dementia services are under-valued in comparison with staff working in other areas of health and social care: this is

supported by work showing that the social workforce is less qualified and less likely to be working towards any qualifications [12]. Findings such as these explain the All-Party Parliamentary Group on Dementia's [13], conclusions in their report on the dementia skills gap:

*'the workforce is perceived to have an inappropriately low status that is exemplified by poor employment terms and conditions and lack of career opportunities. This contributes to a high staff turnover, which militates against workforce development and acts as a huge disincentive to employer investment...'* (page xi)

Another categorisation of stigma includes three categories of stigma experienced by family carers of people with a dementia, namely caregiver stigma, lay public stigma and structural stigma [14]: public stigma is defined as referring to the reactions of lay persons to the stigmatised person; structural stigma encompasses service availability and 'inadequate professional competence'. The latter category of stigma is exemplified by the lack of training of the dementia workforce [12] and under-resourcing of research into dementia [15].

A consensus paper on reducing stigma and discrimination in older people with mental disorders [4] highlighted several important factors in stigma which the authors argue are related to dementia:

- Dementia being seen not as arising from illness but instead as an inevitable part of ageing (which leads to the belief that it can't be treated, and is an inappropriate area for highly skilled medical and nursing attention);
- Popular misuse of the term 'dementia' / 'demented';
- The assumption that people with a dementia have no quality of life and no capacity for pleasure;
- The exclusion of people by virtue of a diagnosis of dementia from some forms of care or treatment eg resuscitation; rehabilitation;
- Loss of 'personhood' which results in personal preferences and beliefs being dismissed;
- Some symptoms are particularly stigmatising eg incontinence; disturbed behaviour.

#### **What do we know about how stigma affects the care of people with a dementia?**

Across European Union countries stigma has been found to influence late presentation to services (through the minimisation and concealment of symptoms), delays in recognition and diagnosis after presentation (through the belief that services had little to offer), and service response to dementia (through therapeutic nihilism and pessimism regarding prognosis) [16]. To this list we can add attitudes to screening [17]; a reluctance on behalf of medical professionals to give the diagnosis perhaps because of the stigma associated with it [18, 19]; an influence on service design so as to separate people with dementia from others [20] (some cultures find the acceptance of care to be inherently stigmatising [21]); and an influence on service resourcing and prioritisation such that care of people with dementia struggles to achieve parity with other services [22, 23].

These factors probably underlie objective 1 of the English National Dementia Strategy [24] states:

*'Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed'*. (page 24)

The Strategy states that the stigma associated with dementia makes it more difficult to talk about, and that this contributes to delay in diagnosis and to the low priority given to dementia care services (we might add here that it also contributes to the low status of staff working in dementia care services [12, 13]).

The Alzheimer's Society investigated the experiences of people with dementia and their families in 2008 [5] by holding a series of focus groups involving people recruited by branches of the Society plus carrying out a small number of interviews: they concluded that

*'The stigma of dementia was very pervasive. Media representation of dementia often did not help but the research indicated that the reaction of people close to them, as well as the responses of professionals, had a more detrimental impact on people with dementia and their carers.'* (page xv)

A YouGov survey of over 2000 people in the UK found that more feared dementia (31%) than feared cancer (27%) or death (18%): retired people worried about health more than other issues and dementia was the condition they most feared [25]. Beliefs influence help-seeking in dementia – this has been shown in studies investigating attitudes of people from minority ethnic communities [26]. The Alzheimer's Society Report [5] highlighted two levels of stigma; external ie in society, the media, amongst the public, including the use of negative language; and internal ie the stigma that people themselves take on in believing that they are less of a person because of the dementia. A person's awareness of their own forgetfulness may cause fear, embarrassment, shame, anger and/or low self-esteem and low self-confidence [27]; a carer may have similar emotional responses. Vernooij-Dassen and colleagues studied eight European countries where they carried out focus groups with professionals having expertise in dementia, and found that stigma appears to be declining in the United Kingdom (UK): they expressed the opinion that one factor in countries where stigma is declining is the existence of strong Alzheimer Societies [16].

A study of the attitudes and practices of general practitioners in Ireland towards the diagnosis of dementia found that stigma plays a role in failure to make early dementia diagnoses [28]. 'Label avoidance' is a term used to describe how people avoid services which might assign them a stigmatising label [29] and there is evidence that health professionals also avoid giving people a stigmatising diagnostic label, for example 'professional resistance' to making a diagnosis of dementia has been described [30], and this phenomenon may underlie low rates of dementia diagnosis so that in England only 31% of people with a dementia were found to be registered on general practice registers [15]

### **How is stigma important?**

One consequence of our attitudes towards people with dementia in seeing them as child-like [7, 31] (for example see Shakespeare's account of late life

*'Last scene of all,  
That ends this strange eventful history,  
Is second childishness and mere oblivion,  
Sans teeth, sans eyes, sans taste, sans everything.'* In As you like it [32])

incapable, or very old and frail rather than people living and coping with a chronic illness, is that decisions about them get made by others and their voices may not be heard. This is not to deny a

need for legislation to allow decisions to be taken on behalf of those who cannot make decisions for themselves, but it is important to recognise that underpinning mental capacity legislation is the requirement that people should be helped to continue making those decisions that they are able to make and to plan ahead for a time they might not be able to make decisions by ensuring that those around them understand their beliefs, priorities and wishes[33]. This is a complex area, but by not making early diagnoses and by failing to fully inform people about a diagnosis of dementia and what the future might hold for them, we are compromising their autonomy and denying them the possibility of shaping their own future care.

People living with dementia can be vulnerable and at risk of harm: they themselves may well be aware of that [34]. We have argued above how stigma distorts services for people with dementia but it also influences services at the level of the individual seeking help eg a person with dementia might be excluded from services in an attempt to avoid labelling them; their wishes may not be sought, not heard or discounted. Thus our assumptions and prejudices about dementia as health and social care professionals might themselves lead to harm, although we ourselves believe that we are motivated by the best of intentions. Similarly family carers might not want difficulties discussed with their relative who is living with a dementia, which precludes that person from making an input into their own treatment and care. One of the concerns about talking with someone about their diagnosis is whether it might lead to suicidal thoughts and/ or acts: a study of suicide in people with dementia in England and Wales found that suicide occurred less often within a year of diagnosis [35] and the authors write:

*'disclosure of diagnosis, although it might evoke suicidal thoughts, is not a risk factor as sometimes suggested.'* (page 178)

Being over-protective is not necessarily in a person's best interests. Making decisions for people and excluding them from taking part in decision-making is not necessarily good practice, however well-intentioned.

Social justice involves recognising the human rights of people with dementia and respecting their dignity throughout the course of their illness. It involves valuing people with dementia in the same way that we value people without [36, 37]. We might question whether our current system of care does this. It appears to prioritise the care of younger people with a single acute illness in terms of resourcing, prioritisation and structure. If hospitals were designed for the care of older people living with multiple chronic physical and mental disorders they would function well for others too.

Ethical non-stigmatising care of people with dementia would be person-centred and would prioritise relational aspects of care such as continuity, kindness and caring empathic staff [38]. Ballatt and Campling [39] have written about 'bringing intelligent kindness to the healing relationship' at the heart of healthcare and the need to rethink the foundation on which care is built: this is especially important in the context of a dementia.

### **What can we do to reduce stigma?**

We have identified four main areas for work to reduce stigma:

#### ***Information and education***

Ignorance is often seen as the basis of stigma and discrimination and education as a priority in combating it. Cheng and co-workers found that brief exposure to information led to a reduction in stigma in a Hong Kong Chinese community sample [40]: they argue that community education has a potentially useful role in reducing stigma and facilitating early detection and diagnosis. Yet Wexler has pointed out that some scientists and medical professionals have exacerbated the stigma associated with Huntington's disease [41] and Byrne has argued that we should aim to change psychiatry first [1]: perhaps more than knowledge is needed, knowledge combined with values or 'education, empathy and tolerance' [42]. Liu and colleagues produced a contradictory argument: they considered that the Asian American tendency to regard dementia as part of normal ageing in effect 'normalised' dementia and led to less stigma [7] in that community. However another study found that Korean American immigrants interpreted dementia as 'insanity', despite tending to 'normalise' dementia as part of ageing [43]. Perhaps, if stigma is to be reduced, the educational message needs to be not only that dementia arises from disease but also that people can be helped by pharmacological and non-pharmacological interventions to live with it [44-46].

People with dementia themselves need information, education and support to be involved as teachers throughout education and training [47, 48]. Cognitive Behavioural Therapy (CBT) has been used to address self-stigmatisation [49, 50] but, although it can be helpful to use CBT, this approach locates the problem within the person and it is appropriate to address stigma across society and services.

Part of the drive to reduce stigma through information and education will involve addressing the role of the media in perpetuating stigma. Thornicroft suggested providing accurate information to the media as one necessary action [10], but we would suggest that other necessary actions include people with dementia, their families and staff working in the field of dementia care being more open to engaging with the media in future.

Education, in the broadest sense, also involves others learning by means of contact with people with dementia. The Nuffield Council on Bioethics emphasises the importance of people with dementia being regarded by others as different (not 'like me') and subject to social exclusion and social isolation [51]. This argument logically leads to support for measures to diminish social isolation and increase social inclusion. The Council argues that they should be encouraged to remain active contributors to society. There is a possible downside to this: some authors argue from research on inter-group contact that increasing contact can decrease the support for social change [52, 53]. Nevertheless the Nuffield Council on Bioethics makes a persuasive case for normalising dementia wherever possible, so that people living with a dementia become a visible part of society and, where they can, are supported to carry on making an active contribution [51], and sets out an ethical framework which consists of six components and is set out briefly in Table 1 [36].

### ***Policy***

Policy at all levels needs to address the need to reduce stigma. Thornicroft argues that the disability-inclusion model is probably the best supported policy approach [10] and has been powerful for people with physical health based disabilities but not well applied to mental health. This model argues that people with disabilities (in this case arising from a dementia) have the same rights as everyone else and it therefore requires respect for their human rights and dignity. A consequence

will be that people with dementia should be consulted, and their voices heard and attended to, on all matters concerning them.

### ***Research***

In the UK we know that research into dementia is underfunded compared with research into cancer [15] and this can be understood as a reflection of stigma, reflecting attitudes towards dementia and the power differential between the two areas of care: the report Dementia2010 found that the cost of dementia to the UK is twice the cost of cancer, three times the cost of heart disease and four times the cost of stroke, yet it receives a fraction of the research funding, namely an annual sum of £50 million is devoted to dementia research in comparison with £590 million being spent on cancer research. In addition to this recruitment of people and families living with a dementia into research studies is likely to be compromised because of a reluctance to talk openly with people with dementia and a tendency for others to protect them. A greater emphasis on research is needed in future. In terms of stigma it would be helpful to establish an agreed operational definition of stigma and to investigate interventions to reduce its impacts on people with dementia and their families.

### ***Service design and delivery***

Dobbs and colleagues looked at changes in residential care/ assisted living which might impact on stigma and highlighted the importance of a strengths-based person-centred approach to care which concentrates positively on respecting difference (person-centredness) in association with attending to the relationships between staff members and residents [20]. To combat stigma services need to shift their emphasis to personhood and relational aspects of care [38], involving people with dementia in their care at all stages of their illness [51, 54], inviting their involvement in service design and improvement, and hearing their spoken and unspoken voices.

Differential resourcing which puts care of people with dementia low down the list of priorities is stigma in action. Failing to value, train and support the staff working with them only compounds the problem.

### ***Conclusion and future perspective***

Reviewing the literature shows that stigma, in terms of stereotypes, prejudices and discrimination, continues to impact on the care of people with dementia and their families and to affect service status, resourcing and staffing. As the population ages, dementia is becoming an issue which cannot be ignored as the numbers of people with dementia in the UK and around the world are projected to increase. This increase in numbers of people living with dementia is likely to compound the difficulties of stigma unless its effects on people and services are addressed. People with dementia and their families are speaking out individually and through Alzheimer Societies: they are likely to become an even more powerful lobby group in the future. By coming out of the shadows and speaking up, they are directly confronting the stigma associated with dementia and educating the public about the condition. Professionals and others also need to confront the stigma of dementia and avoid reinforcing it by their actions. To further combat stigma and provide for the future person centred care of people who develop a dementia will need concerted effort in four areas: policy, research, information and education, and service design. We would do well to remember that these are not 'other' people, in the future this could be us – what would we want for ourselves?



### **Financial and competing interests disclosure**

Susan Mary Benbow works for Older Mind Matters Ltd and is Visiting Professor of Mental Health and Ageing at Staffordshire University.

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Neither author has any relevant financial involvement with any organization or entity with a financial interest in, or financial conflict with, the subject matter or materials discussed in this paper.

Pre-publication draft

**Table 1: Components of the Nuffield Council on Bioethics ethical framework for dementia [36] and implications for practitioners**

Component	Brief description	Implications for Practitioners
1	A case-based approach to ethical decisions.	The Nuffield Council ethical framework for dementia can be used to inform ethical decision-making.
2	Belief that dementia arises from brain disorder.	The disability-inclusion model argues that people with disabilities have the same rights as everyone else and it requires respect for their human rights and dignity – this is not incompatible with understanding that dementia arises from brain disorder.
3	Belief that with care and support people with dementia can be supported to have a good quality of life.	Although there is no cure for dementia in most instances, there is much which can be done to influence how people live with it by informed, intelligent good practice. Services designed to care for (older) people living with multiple physical and mental disorders including dementia, will serve others well too.
4	The importance of promoting the interests and well-being of both people with dementia and their carers.	People with dementia should be supported to remain involved in society and to express their thoughts, feelings and views. Family and professional carers of people with dementia are valuable individuals who have voices which should be heard and respected. The avoidance of people who are ‘not like me’, namely old and mentally slow, can result in neglect, lack of kindness and social exclusion. Clinicians should be aware of and resist the tendency to diminish, devalue and socially exclude people living with a dementia.
5	Requirement to act in accordance with solidarity <sup>1</sup> .	People with dementia should be supported to remain involved in society and to express their thoughts, feelings and views. Clinicians should be aware of and resist the tendency to diminish, devalue and socially exclude people living with a dementia.
6	Recognition of the personhood, identity and value of the person with dementia.	People with dementia should be supported to remain involved in society and to express their thoughts, feelings and views.

<sup>1</sup>solidarity is defined by the Nuffield Council on Bioethics as ‘*the idea that we are all ‘fellow-travellers’ and that we have duties to support and help each other and in particular those who cannot readily support themselves*’. [36] (page 29)

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Pre-publication draft