

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

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Abstract

This paper provides a review of the literature on the reality of living with a diagnosis of dementia in terms of stigma and ageism, and their effects on care.

Key words

Dementia, stigma, ageism

Reference

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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.

Counting the Cost (Alzheimer's Society, 2009), explored carers' perceptions of dementia care in hospital settings and identified several key areas of dissatisfaction.

These included nurses not recognising or understanding dementia; a lack of person centred care; patients not being helped to eat and drink; a lack of opportunity for social interaction; not as much involvement in decision-making as wished for (for both the person with dementia and carer); and the

person with dementia being treated with a lack of dignity and respect.

Recent evidence from the Francis report (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013) described a culture of secrecy and defensiveness, in which there was an absence of human kindness and disinterest in family and carer concerns.

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). The main strands of the strategy set out recommendations which would enable people to 'live well' with dementia.

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

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 pervading 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.

Bowling (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 of working age, who had dependent children and mortgages to consider in relation to their diagnosis and future lifestyle (Pratt and Wilkinson, 2001; Alzheimer's Society, 2012).

Dementia is vastly underdiagnosed within the UK (National Audit Office, 2007) and it is suggested that there needs to be a wholesale cultural change in public awareness to reduce stigma and encourage people to see their GP regarding memory problems (Alzheimer's Society, 2012).

However, many of the participants within the studies had encountered challenges and some described dismissive and unhelpful attitudes from a range of health professionals, including GPs who were reluctant to either consider dementia or refer onto specialist mental health services.

However, diagnosing dementia is not a straightforward process and individuals are

not normally diagnosed by their GP in primary care. If signs of dementia are present then a person would normally be referred by their GP to a specialist at a memory clinic where screening, assessments and scans would be undertaken.

In some cases it was clear that dementia was not considered for younger individuals because of the common misconception that dementia was only associated with older age (Alzheimer's Society, 2008) and it was clear from the literature that participants had to be extremely vocal and persistent to get referred onto specialist services.

Although it is evident that early and timely diagnosis is essential in enabling decision making and choice for individuals living with dementia, another factor that could impede a timely early diagnosis was a reluctance on behalf of GPs to diagnose a condition for which there is no cure and that they believed would be too distressing for the individual concerned (Alzheimer's Society, 2008). This is often referred to as 'therapeutic nihilism'.

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.

Moore and Cahill's (2013) recent study on GPs disclosure of a dementia diagnosis in two countries, Sweden and Ireland highlights this issue distinctly. Although GPs from both groups were aware of the evidence that early diagnosis is good practice, important and

“ Stigma and discrimination are evident in the care that younger people receive ”

broadly 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.

Davis, in his autobiographical account *My journey into Alzheimer's* (1989: 121) spoke of 'death before death', while Cohen and Eisdorfer (1986) discuss a loss of self and Henderson (1998) tries to articulate 'the in-between status of the person'.

This pervasive negative theme is also acknowledged in Katsuno's study (2005) where participants clearly identified that

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

- Adams T. (2010) The applicability of a recovery approach to nursing people with dementia. *International Journal of Nursing Studies* **47(5)**: 626-34.
- Alzheimer's Society. (2008) *Dementia: Out of the shadows*. Alzheimer's Society: London.
- Alzheimer's Society. (2009) *Counting the Cost: Caring for people with dementia on hospital wards*. Alzheimer's Society: London.
- Alzheimer's Society. (2010) *My name is not dementia*. Alzheimer's Society: London.
- Alzheimer's Society. (2012) *Dementia 2012: A National Challenge*. Alzheimer's Society: London.
- Audit Commission. (2004) *Older People – Independence and Well-being: The Challenge for public services*. Audit Commission: London.
- Beauchamp TL, Childress JF. (1994) *Principles of Biomedical Ethics*. (4th Edition). Oxford University Press: Oxford.
- Beeston D. (2010) *Early Interventions in Dementia*. Centre for Ageing and Mental Health, University of Stafford: Stafford. Available at: www.qihub.scot.nhs.uk/media/162464/early-intervention-in-dementia-a-review.pdf (Accessed 25 August 2014).
- Bowling A. (2001) An "inverse satisfaction law"? Why don't older patients criticise health services? *Journal of Epidemiology and Community Health* **56(7)**: 482.
- Brooker D. (2007) *Person centred dementia care: Making services better*. Jessica Kingsley Publishers: London.
- Care Quality Commission. (2013) *Care Update Issue 2*. available at: www.cqc.org.uk/sites/default/files/media/documents/cqc_care_update_issue_2.pdf (Accessed 28 October 2013).
- Clarke C. (2000) Rationing scarce life-sustaining resources on the basis of age. *Journal of Advanced Nursing* **35(5)**: 799-804.
- Cohen D, Eisdorfer C. (1986) *The loss of self: A family resource for the care of Alzheimer's disease and related disorders*. Norton: New York.
- Collier E. (2005) Latent Age Discrimination in Mental Health Care. *Mental Health Practice* **8(6)**: 42-5.
- Davis R, Davis B. (1998) *My journey into Alzheimer's disease*. Wheaton Publishers: Illinois.
- Department of Health. (2005). *Mental Capacity Act*. HMSO: London.
- Department of Health. (2009) *The National Dementia Strategy*. Department of Health: London.
- Gilchrist C. (1999) *Turning your back on us: older people and the NHS*. Age Concern: London.
- Gillon R. (2003) *Philosophical Medical Ethics*. John Wiley & Sons: Chichester.
- Goffman E. (1963) *Stigma: Notes on the management of a spoiled identity*. Penguin: London.
- The Guardian. (2013) Asda withdraws 'mental health' Halloween costume. Available at: www.theguardian.com/business/2013/sep/26/asda-mental-patient-costume (Accessed 12 October 2013).
- Henderson CS. (1998) *Partial view: An Alzheimer's journal*. Southern Methodist University Press: Dallas.
- Innes A. (2009) *Dementia Studies: A social science perspective*. Sage Publications: London.
- Katsuno T. (2005) Dementia from the inside: how people with early-stage dementia evaluate their quality of life. *Ageing and Society* **25(2)**: 197-214.
- Katz J, Holland C, Peace S. (2013) Hearing the voices of people with high support needs. *Journal of Aging Studies* **27(1)**: 52-60.
- Kitwood T. (1997) *Dementia Reconsidered: The person comes first*. Open University Press: Buckingham.
- Kitwood T. (1997a) The Experience of Dementia. *Ageing and Mental Health* **1(1)**: 13-22.
- Moore V, Cahill S. (2013) Diagnosis and Disclosure of dementia – A comparative qualitative study of Irish and Swedish General Practitioners. *Ageing and Mental Health* **17(1)**: 77-84.
- Moyle W, Venturo L, Griffiths S, Grimbeek P, McAllister M, Oxlade D, Murfield J. (2011). Factors influencing quality of life for people with dementia: A qualitative perspective. *Ageing and Mental Health* **15(8)**: 970-7.
- National Audit Office. (2007) *Improving services and support for people with dementia*. Available at: www.nao.org.uk/report/improving-services-and-support-for-people-with-dementia (Accessed 9 October 2013).
- NHS Institute for Innovation and Improvement. (2013) *The right to care – call to action*. Available at: www.institute.nhs.uk/qipp/calls_to_action/the_right_care_call_to_action.html (Accessed 30 November 2013).
- Parker C, Philip I. (2004) Screening for cognitive impairment among older people in black and minority ethnic groups. *Age and Ageing* **33(5)**: 447-52.
- Pinner J, Bouman WP. (2003) What should we tell people about dementia? *Advances in Psychiatric Treatment* Available at: www.aptrcpsy.org/content/9/5/335.full (Accessed 24 August 2014).
- Pratt R, Wilkinson H. (2001) *Tell me the truth: The effect of being told the diagnosis of dementia from the perspective of the person with dementia*. Mental Health Foundation: London.
- Robb C, Haley WE, Becker MA, Polivka LA, Chwa HJ. (2003) Attitudes towards mental health care in younger and older adults: similarities and differences. *Ageing and Mental Health* **7(2)**: 142-52.
- Royal College of Nursing. (2013) *Mid Staffordshire NHS Foundation Trust Public Inquiry Report – Response of the Royal College of Nursing*. Available at: www.rcn.org.uk/_data/assets/pdf_file/0011/530948/004477.pdf (Accessed 20 August 2014).
- Royal College of Psychiatrists. (2009) *Position Statement: Age discrimination in mental health services: making equality a reality. PS2/2009*. Royal College of Psychiatrists: London.
- Shepherd G, Boardman J, Slade M. (2008) *Making Recovery a Reality*. Sainsbury Centre for Mental Health: London.
- The Mid Staffordshire NHS Foundation Trust Public Inquiry. (2013) *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry. (Chair: R Francis): Executive summary*. Stationery Office: London. Available at: www.midstaffpublicinquiry.com/sites/default/files/report/Executive%20summary.pdf (Accessed 13 November 2013).
- Timulak L. (2008) *Research in Psychotherapy and Counselling*. Sage Publications: London.
- Wilmot S. (1997) *The Ethics of Community Care*. Cassell: London.