Dementia, dignity and quality of life: nursing practice and its dilemmas

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Aims. The need for healthcare practitioners to respect the dignity of older people is widely recognised in England, where it has been given attention by politicians, professionals and health service regulators. This article aims to provide examples of how such ambitions may be used in practice development.

Methods. This article reports the use of five vignettes discussed by dementia care practitioners that explored the areas of dementia diagnosis, lying, incontinence, behavioural and psychological distress, and end of life care.

Findings. Each vignette promoted discussion of differences of perspectives about the ways to enhance the dignity of people with dementia in hospital, care home and community settings. The discussion confirmed that while dignity may be one quality indicator of good care potentially enhancing quality of life, it is not always straightforward. It may be more easily conceptualised when talking of physical care and treatment than other areas.

Conclusion. The opportunity to debate the subject and to discuss practice examples revealed differences of opinion and moral perspectives between...
Dignity is described by researchers from different countries as an integral component of quality of life (QOL), particularly in nursing home settings (Degenholtz et al., 2007; Mittal et al., 2007; Kane et al., 2003) and in end of life care (Stewart et al., 1999). Frequently also associated with quality of care, ‘dignity’, as it applies in nursing facilities, is defined as a ‘feeling experienced by residents’, as well as ‘status conferred on residents’ (Kane et al., 2003). Incorporated within the cluster of QOL domains related to self-worth and individual agency, dignity is further associated with individuality, autonomy and privacy (Kane et al., 2003). Stewart et al. (1999) suggested that dignity also incorporates ‘self-presentation’ or the ‘sense of being valued as a person, sense of not being a burden, body image and sense of being attractive’. The association of dignity with QOL has led to the suggestion that violation of an individual’s dignity will result in deterioration in their QOL (Post, 1995). Therefore it is important to consider dignity when exploring QOL and vice versa.

All care professionals are encouraged to develop their skills and attitudes in environments where dignity is respected; to learn to practice in a way that dignity is not impeded; to involve users and respect their preferences; and to learn how to change the environment so it does not threaten older people’s dignity (Askham, 2005). Above all there is widespread consensus that nurses need to provide dignity in care and have leadership roles in its promotion (Woolhead et al., 2006; Gallagher et al., 2008; Royal College of Nursing, 2008; Baillie & Gallagher, 2009). In a developmental learning project in Sweden, Randers and Mattiasson (2004) concluded that the concepts of autonomy and integrity appeared to presuppose one another and were indivisible in maintaining older people’s dignity in hospital settings. They argued that if older patients’ autonomy is supported, then their integrity is protected and, consequently, their dignity upheld.

Despite a rather weary comment that the term ‘dignity’ was becoming so commonplace in health care documents that ‘phrases such as ‘respect for human dignity’, ‘treatment with dignity’, ‘death with dignity’ and the ‘right to dignity’ were in danger of becoming clichés; ‘especially so in the context of older people’ (Tadd et al., 2002), interest in dignity remains. This may be because of the powerful evidence of lack of dignity reported by many patient and healthcare inspectors. In response to these concerns, the English Department of Health embarked upon a Dignity in Care Campaign. (see http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Dignityincare/DH_065407). The campaign includes a set of principles about dignity (the Dignity Challenge), a National Dignity Ambassador with the aim of increasing the media profile of dignity, National Dignity Tours by the government Minister for Care Services, a Dignity in Care practice guide in electronic format, a measurement system for the grading of hospitals’ regard for dignity and respect among its older patients, a Dignity in Care Public Survey (DH 2006b), and the Queen Mother Award for Dignity in Care.

These different activities reflect the academic literature’s conceptualisation of the term dignity as a multi-faceted concept, like quality of life. It includes: (i) dignity of identity (self-respect/esteem, integrity, trust); (ii) dignity as a human right (equality, choice); and (iii) dignity as an expression of autonomy (independence, control). In the focus group discussions held by Woolhead et al. (2006) similar views about dignity were expressed by older people across a number of European states. Examples of dignity being jeopardised, rather than being enhanced, were easily identified by the older participants, who reported experiences of feeling patronised, excluded from decision-making, and being treated as ‘objects’. Many felt that government policies did not support their rights to dignity. Such perceptions seemed specially related to problems or negative experiences with communication, privacy, support for personal identity and feelings of vulnerability in healthcare settings.

However, these examples and the focus on dignity as part of patient experiences serve to highlight the different use of the term in certain contexts and relationships. Definitions of dignity, for example, and debates about its role as a barometer of patient experiences or a symbol of human worth, are hugely wide-ranging (see Macklin, 2003; Help the Aged, 2008) and hard to research (Hall et al., 2009a). For nurses working in dementia services it is important to explore if dignity is used as a synonym for person-centred care, as a measure of QOL and whether there are aspects of dementia that raise particular perspectives about the construction of what is dignity in care. Such an understanding may help practitioners about the use and relevance of the term dignity. These need to be acknowledged in any debates about objective and subjective definitions of quality of life.

Key words: dementia, dignity, ethics, nursing, older people, quality of life
better support older people with dementia and their carers, and thus improve their QOL. This paper reflects these debates.

While the focus of this paper is on dementia care, much of what is discussed is relevant to all older people’s nursing, and other services. The National Service Framework for Older People (Department of Health (DH) 2001 encouraged personalised responses to the health and social care needs of older people, the treatment of older people with dignity and respect, and the removal of age discrimination in England. Reviewing these aspirations, in the report A new ambition for old age, the DH (2006a) recognised further need for changes of attitudes towards older people so they are valued and respected. The links to improving the quality of life (QOL) for older people generally were reinforced because of the concerns that their quality of life is particularly compromised; especially among older people who are ill, have long-term conditions or are disabled. Illustrations of lack of dignity in older people’s services were evidenced in the Healthcare Commission (2007) report on dignity in hospitals. This found that older people were not always treated with dignity by health professionals, they lacked information and their wishes were sometimes disregarded. Some staff also exhibited ageist attitudes, were not aware of the need to sustain dignity or had not received any training in how to promote dignity in care. The Healthcare Commission (the regulator of health services in England, now the Care Quality Commission, 2009) continued to focus on dignity as a key theme in its inspection programme of 2006–2007 to assess how National Health Service (NHS) Trusts are meeting its standards relating to dignity in inpatient settings. The Care Quality Commission uses the guidance of Standards for Better Health (DH 2004) to examine dignity through a specific standard, ‘dignity, consent and confidentiality’ (C13). As this paper maintains, such terms are frequently found in definitions of quality of life (QOL) and there seems much to be gained by linking dignity debates with quality of life theories.

Focus on dignity has not been confined to the NHS nor is it simply a political slogan. It has acted as a reminder to some nurses working in the NHS, statutory social care and the independent sectors of care and treatment that there should be ‘zero tolerance’ of views and practices that undermine dignity. The following quotation illustrates the political importance of dignity and human rights in England currently:

Although overt age discrimination is now uncommon in our care system, there are still deep-rooted negative attitudes and behaviours towards older people. Within five years, our ambition is to ensure that older people and their families will have confidence that in all care settings, older people will be treated with respect for their dignity and their human rights’. [Liam Byrne, Ministerial foreword to A New Ambition for Old Age (Department of Health, 2006a)]

Methodology

This paper reports on a workshop that took place at a UK national networking conference for dementia care practitioners and service managers held in autumn 2008. The two hour workshop aimed to provide the opportunity to discuss experiences and expectations about dementia and dignity. The workshop format had been devised by the research team who has considerable experience with the approach (Manthorpe et al., 2007) and professional education. It was further informed by literature evaluating inter-professional learning (Carpenter & Dickinson, 2008). The main objective of the workshop was to seek participants’ views and analysis of where the problems with maintaining dignity in dementia services currently lie. The workshop was introduced and chaired by a person with dementia who is an advisor to the research programme for which the workshop was a preliminary. Participation in the workshop was voluntary.

A modified nominal group method was used, in which a facilitator directed the discussion to consider a number of questions, and focused attention on achieving a common understanding of these questions, and their answers, without forcing the group to prioritise or rank understandings (Murphy et al., 1998). A nominal group technique designed for complex problems was chosen, to allow small groups of workshop participants to debate the questions and to contribute from their own experiences (Dockery, 2003). Individuals were given the opportunity to debate dignity in the five areas of: dementia diagnosis, lying, sexuality, smell and end of life care. These were chosen to reflect matters that commonly arise in discussion of dignity in dementia care and its violations (see, for example, Jacobsen, 2009). Workshop participants were able to choose the topic of their choice. Seventy participants, almost all working in dementia services and the majority with nursing qualifications, attended the workshop, with the topic of end of life care being the most popular choice and forming the largest group.

The workshop format had been devised by the research team, based on experiences with professional education and informed by literature evaluating inter-professional learning.

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Maintaining dignity in diagnosis

Findings

Dementia diagnosis disclosure

The first vignette addressed the disclosure of dementia (see Box 1). Two clear sets of views emerged in discussion. The majority view was that this was a situation in which it would be important for the General Practitioner (GP) or family doctor to maintain the trust and confidence of Mr Wood. While it was important for Mr Wood’s family to know of his diagnosis, it was equally important for there to be time to talk to him about ways of discussing his diagnosis with his family in ways that would maintain his dignity. The main objective at the moment was not to disclose the diagnosis but to enable him to think about the way in which he might best break the news to his family. However, a minority view was that it was appropriate to override Mr Wood’s wishes. These participants thought that the GP should not collude with Mr Wood and should try to persuade him that it would be in his and his family’s best interests if the family learned what the matter was. However this group also argued that the GP should not be dishonest and, if Mr Wood’s daughter asked the GP what was her father’s problem the GP should suggest that the daughter talk to her father about this.

One participant suggested that the GP might think about whether discussion with Mr Wood would be best if undertaken with a person of the same gender so that this might reduce Mr Wood’s possible feelings that ‘women were fussing’. Again, some participants thought that the best approach would be to tell his daughter to ‘be patient’ and to take the time to use therapeutic approaches with Mr Wood to talk about the diagnosis. Participants recognised that Mr Wood’s feelings might be related to possible threats to his dignity that he was already experiencing, but could also be related to his need to feel in control.

Dignity around disclosure of dementia diagnosis was recognised as important in the context of efforts to improve early recognition of dementia. This was seen to be a priority area as the ageing of the population will increase the numbers of people attending for assessment in memory clinics and other settings in England (DH, 2009). Larger numbers of patients and a consequent greater throughput will perhaps mean practitioners in such services may actually spend less time with individuals.

Lying

The second vignette in Box 2 (Mrs Brown) elicited agreement that this type of encounter was not uncommon. Participants gave further examples from practice in care homes: one reported an arrangement whereby a resident paid for his bottles of beer with money supplied by his son who was then reimbursed by the care home manager in a circular transaction. Another recounted how a resident would not eat her meal unless she paid the matron for it and how the staff managed this arrangement without undue fuss. A further example came from a care home manager who described
Box 2 Lying

Mrs Brown has been helping out at a local older people’s social centre run by a voluntary group for a couple of years. She receives a ‘wage’ from the centre, a five pound note in an envelope, from the centre organiser for her work. This money is, in fact, given to the centre by Mrs Brown’s daughter in addition to the centre’s fee. This arrangement seems to work well until a member of staff tells Mrs Brown that people have been lying to her and she is a fool for believing in this pack of lies. Mrs Brown is distressed and is too ashamed to go to the Centre.

1. How are people’s dignity being supported and undermined in this scenario?
2. How do we deal with conflicts about dignity and its interpretation?
3. What would you do? As the centre manager? As Mrs Brown’s daughter? As Mrs Brown?

Box 3 Sex and intimacy

Tom and Ethel have been married for 60 years. They both have dementia and now live together in a residential home. Tom has mild Alzheimer’s disease, but Ethel has more advanced disease and has difficulty consenting for basic aspects of care. One evening Tom and Ethel are found by a member of staff having sexual intercourse. Ethel appeared to be happy but the staff are concerned that she does not have capacity to consent for sex.

What potential violations of dignity arise here?
How should the staff ensure dignity is maintained?
Safeguarding) Investigation being opened. This vignette addressed the subject of sexual relationships and the role of family carers and staff in maintaining dignity around this issue.

Given the workshop groups were self-selecting, this group showed some surprisingly polarised views. Many participants were in favour of the principle that people with dementia should be ‘allowed’ to have sexual relationships, although some felt that a lack of capacity to consent to sex may constitute rape even within marriage and where neither party was dissenting. Some participants raised concerns about the difference between care home staff passively allowing sexual intercourse between residents and actively facilitating it, and the legal and ethical concerns raised by the latter. As the workshop delved further into these issues, such as providing dedicated space, romantic environment, sex toys and lubricant, greater numbers of participants became more uncertain of what was right and others appeared to become uncomfortable about discussing these matters.

Different meanings of the word ‘dignity’ emerged in this discussion; it can signify worthiness or respect by others, or it can synonymise self-respect. This group highlighted these two definitions; is the ‘dignity’ in question self-referent (i.e. ‘I want to have sex and consider this to be part of my being and hence dignity’) or referent to a wider group (‘that couple are having sex, it’s not very dignified’)? Participants began by conflating these meanings, but as the group discussion progressed and the differences inherent in the meanings became apparent, greater clarity of these different interpretations emerged.

As a group, participants were unable to agree what constituted ‘informed consent’ for sexual intercourse. This led to a debate about whether one would have had greater concerns if the relationship was new (some participants reported residents developing a sexual relationship for the first time in care homes) rather than one established before the onset of dementia. Concerns were also raised about whether to involve relatives, particularly adult children, in discussions about capacity and risk. There was acceptance among participants that capacity to agree to sexual activity will fluctuate, and probably deteriorate over time, but no clear ideas of how to police the presence of capacity, or what to do if it became known that residents were having a sexual relationship.

Hygiene and personal care

Workshop participants had different practice experiences within dementia services. Their initial response from reading the vignette (Box 4) about Ann Laurel was that this was a very difficult but familiar problem. Participants were wary of making assumptions as little detailed information was given about Ann as an individual and her situation. They noted there could be many reasons for this apparent problem, depending on the person’s situation, for example, prescribed medication taken (side-effects), physical problems (e.g. urinary tract infection), volume or type of liquids consumed, physical aids to get to the toilet (functional), not getting to the toilet in time (urgency) and general health could all affect Ann’s situation.

Participants debated whether Ann was hiding her problems, trying to manage and contain the smell or leakage herself, but finding it difficult, or whether she did not want to admit she had a problem to preserve her privacy, had little or no insight, or indeed may even had little or no sense of smell. Many were able to reflect on their experiences of similar situations. One participant described how a care home resident had used rags instead of incontinence pads, as this was her preferred method of managing the problem. Although others viewed this strategy as insufficient, the participant considered it the client’s right to use the method which she considered most acceptable. There was a consensus among the group members that this was a matter of an individual’s choice, even if it did not work effectively.

The group then debated the balance between respecting a person’s choice and duty of care to the individual. They found it difficult to give a definitive answer but considered ensuring the person was not at risk of skin problems and infections. In a community setting, such as the vignette described, the same debate has different nuances regarding balancing dignity with responsibilities to other people. In terms of maintaining dignity, participants identified the luncheon club volunteers as a source of support for Ann. They could broach the problem with her, or prompt her to use the toilet at regular intervals. However, much depended on the volunteers’ relationship with Ann, and whether it was appropriate for volunteers serving food to help her manage her incontinence. Most of the group agreed that the staff member who knew her best would be the right person to
approach Ann and discuss the problems. This might be the person who referred her to the luncheon club, for example, or a community nurse, social worker or her GP. Group members considered the possibility that Ann might actually feel relieved to have her problems addressed and supported.

The group then discussed how to manage the responses and reactions of other luncheon club users. Negative comments were thought likely to affect Ann’s dignity, pride and self-esteem. One participant thought that this might be best managed by providing an educational-awareness forum to raise personal care issues in a group setting. Training also could be provided for staff/volunteers; but as one member of the group was eager to highlight, training should not simply be about teaching and education but a vehicle to make change and challenge attitudes.

Most in the group drew on their work and family caring experiences and concluded that if put in a similar situation to Ann’s they would want to be told that they had an odour about them but that it would have to come from a person they trusted and to whom they felt close. Overall the vignette posed a real and common challenge for the group but participants agreed that it was important to balance individual choice and dignity, with individual needs and duty of care.

End of life care

Discussion about this vignette (Box 5) considered how the different views and priorities of the GP, care home staff and Mr and Mrs Lewis had influenced the care that Mr Lewis received. Many felt the key to the story was that the decision to move Mr Lewis to a care home had not been supported by Mrs Lewis and this had been compounded by care home staff not being able to meet with the family before Mr Lewis moved in. Some felt the situation might have been helped by having someone to act as Mr Lewis’ advocate, both at the time of deciding whether or not he could stay at home and when trying to implement the advance care plan. One member of the group commented that no-one seemed to have thought about Mrs Lewis’ needs for support, even though they assumed the GP was acting in her best interests when he suggested Mr Lewis move to a care home.

The failure to provide Mr Lewis with appropriate pain relief was seen as a major failure of care and one where the needs of Mr Lewis had been overlooked because staff were not confident in how to respond to Mr Lewis’ symptoms and Mrs Lewis’ expectations. The lack of pre-admission planning or acknowledgement by the GP or care home staff that Mr Lewis was dying seemed to contribute to a confused approach to care. Several participants commented that staff were probably trying to be caring and would have been very uncomfortable not giving Mr Lewis fluid. Others observed that often it was difficult for care home staff to do what was best for the older person and their relative. They also speculated whether care home staff had wrongly interpreted Mrs Lewis’ requests as her wanting them to hasten her husband’s death. They felt the vignette highlighted a common situation when care home staff feel vulnerable in making decisions on behalf of residents and the tendency, in emotionally charged situations, to miss out on the dignity and needs of the person with dementia, as concerns about personal liability and responsibilities for decision making dominate. Some participants commented that the advance care plan might have alienated staff because it did not seem to be something that could inform care planning. They felt that care home staff and Mrs Lewis should have received better support from nurses and the GP in particular, and one participant said that in a similar situation they would have involved their local palliative care nursing service.

Group members observed that it was generally easier to write an advance care plan than implement it and people’s views and feelings often changed over time. The group was undecided how common this kind of situation was in care home settings. Some felt it was a familiar story; others believed that this was a situation that could have easily been avoided and that most care homes would not admit an older
person with dementia who was dying without making sure that there was an agreed care plan in place that had involved the relatives and other healthcare professionals. Through this process, they felt that the dignity of the person was more likely to be respected. Overall this was one scenario where participants did not feel the concept of dignity was explicitly part of the discussion; participants felt they were focusing on the ability to work with residents and relatives; and to provide both with good quality support.

Discussion

There are many depictions of loss of dignity that reflect bad practice, insensitive practitioners and near abusive attitudes (Jacobsen, 2009). However, the instances discussed in this workshop revealed some of the complexities of practice encountered internationally, in what others have described as work that involves living with ethical dilemmas and sometimes moral distress (Kalvermark et al., 2004).

Nursing practice has an ethical basis of concern with the autonomy, privacy and dignity of people using services. Even before ‘dignity’ became the apparent hallmark of what older people wanted from health and social care, good practice in dementia care recognised needs for dignity often in the context of QOL, but also acknowledged potential tensions between these requirements and the importance of thinking broadly about dignity both at the moment and in the context of relationships (Hertogh et al., 2004).

These dimensions arose in discussion about a number of the illustrative examples. In relation to the disclosure of dementia between family members in vignette 1, the source of tensions were related to Mr Wood’s defences and the potential for his dignity and QOL being undermined by the consequences of not adjusting to his changing abilities in social settings, as well as his perceptions of the potentially stigmatising reactions of others and his fear of loss of control. In many ways this reflects some of the lay understandings of dignity, that it is associated with pride, and that to be on ‘one’s dignity’ (a colloquialism for being proud but possibly isolated) may not be a happy social experience.

In the second vignette, the situation of lying to someone with dementia might on the face of it seem infantilising. However, practitioners thought of ways in which a person’s best interests and QOL could be maintained by agreement that their dignity might be best served by apparent deception – or the sharing of their world. To outsiders this practice might be judged negatively and there is a debate about truth telling in dementia which reveals that this is an area where staff face dilemmas and seek to work in consensus, engaging the wider care team and others (Woods & Pratt, 2005).

The third vignette touched on an area where there is a legal framework in England and Wales (Mental Capacity Act, 2005) as well as practice guidance. Three conclusions were drawn from this workshop; differing views about people with dementia having sexual relationships, with most practitioners advocating facilitation as part of QOL but a few preferring prohibition; the uncertainty about how to balance an individual’s right to sexual expression (and a couple’s right to sexual intercourse) with the right not to be subject to unwanted sexual acts; and lack of clarity about defining capacity to engage in sexual acts or the legal framework applicable. Interestingly, few of the practitioners touched upon the strict application of the law and professional responsibilities (e.g. the Sexual Offences Act 2003 or Mental Capacity Act 2005) but were concerned with both the dignity of adults to have consensual sexual relationships, the expression of sexuality as part of QOL and the infringement to dignity that might occur if this were denied.

Taken together, the discussions around the vignettes revealed that while infringements of dignity or human rights requirements may be visible, the enforcement of such rights is, at times, not straightforward. Indeed the language of enforcement may frame discussion in a certain way, foreclosing debate about more psychotherapeutic options, for example, being suggested as promising by Hall et al. (2009b) or marginalising dignity as part of QOL. Dignity or loss of human rights cannot work solely through individual enforcement when there is uncertainty over what is the balance between dignity and duty of care, or individual actions in a communal setting as in vignettes 4 and 5. While many governments take responsibility for the enforcement of standards through guidance, inspection and regulation, and nurses need to understand human rights principles, including accepting challenges to the standard way of doing things and adapting their practices in response, they recognise that there are areas of uncertainty. If everyday nursing practices, such as providing support with toileting, end of life care and sharing information, do not seem on the face of it to promote dignity and overall QOL, they may be challenged by people using services and their families or advocates. This will require responses from frontline nurses and others.

The discussions also revealed the potential for debate not just between nurses and people with dementia and their carers, but within inter-professional teams and workplaces. Such debates are also proposed by researchers investigating the many different definitions of the concept of QOL and particularly which domains of QOL are considered important by people with dementia and which are possibly based on opinions of other people, such as family members, or theoretical models (Droes et al., 2006). This was most
evident in the vignettes concerning lying (vignette 2; care home settings) and continence (vignette 4; day care setting, including volunteers). Multiple and conflicting perspectives can arise within teams about what is dignified or what is QOL or how to put this into practice. As some of the discussions illustrated, this debate may touch on deeply held personal beliefs or ethical principles.

This paper demonstrates the value of using common but real life or ‘authentic’ examples of dilemmas in nurse education, staff development, and in shared learning across sectors and professions. There may be value in engaging with people with dementia and carers to explore the translation of concepts such as dignity and QOL into specific care or support plans and into the ethos of a care or treatment setting.

**Conclusion**

The focus on dignity in care settings for people with dementia and older people overall is an international phenomenon which has recently found political favour in England and is now used by regulators and politicians as a means of defining good quality care. However, dignity is a broad concept and its dimensions need measuring to make it workable. As the discussions of vignettes reported here shows, the apparent simplicity and presumed shared understanding of what dignity is about are revealed when practice examples are scrutinised and it is linked to QOL. Nurses have extensive experiences of the complexities of interactions with older people with dementia when there are multiple expectations or when principles are potentially conflicting. As an indicator of good care and ways to promote QOL, dignity helps services to meet their responsibilities to older people with dementia within a framework of human rights that are potentially enforceable. It would be wrong however to see dignity as one dimensional and practitioners, whose performance may be judged by it, should ensure its many meanings are widely understood.

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