Bodywork in dementia care: recognising the commonalities of selfhood to facilitate respectful care in institutional settings

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Introduction

The global increase in the incidence of dementia (Alzheimer Disease International 2009) has been a driver for national policies aimed at addressing financial, educational and quality of life concerns of people with dementia and those who support them (Department of Health 2009; Norwegian Ministry of Health and Care Services 2008; Republique Francaise 2008). In the United Kingdom (UK), one of the consequences of such policies is that people with dementia are supported to remain at home for longer. Therefore care homes are admitting more very frail people with complex needs such as dementia; putting additional strain on an already stretched and sometimes inadequately skilled workforce (Care Quality Commission 2012)

(CQC). While care inspections generally reveal good practices (CQC 2012), there are areas for concern in the care of older people and people with dementia, particularly relating to ensuring dignity (CQC 2012) and knowing enough about the person to inform good care (Care Commission/Mental Welfare Commission 2009). Kelly (2007), in an ethnographic study of people with dementia in a UK hospital noted many incidents of poor practice, including the incident described below:

Hardly had the toilet door closed when I heard Florence[i] shouting and then the care worker shouting back. Two other staff move quickly to the toilet and it becomes suddenly noisy. Loud voices and underneath, the sound of Florence wailing. Suddenly the toilet door opens and out comes the care worker, backwards, with Florence facing her and pushing her with her arms outstretched. The care worker is half laughing, half cross, but Florence is distressed "Oh me, me". Two staff manoeuvre Florence further down the corridor and leave her there sobbing. (Kelly 2007)

Seven years later, a British Broadcasting Corporation (BBC) television programme revealed some shocking practice in a UK care home (BBC 2012), prompting the question 'why does such abusive practice still happen and how can it be stopped?'

Such poor practices are not confined to the UK as evidenced by Schiamberg *et al.* (2012) who identified that 24.3per cent of interviewees from a random sample of 452 relatives of older people in care homes in the United States reported at least one incident of physical abuse of residents by care home staff. Cohen *et al.* (2010) in a

study of abuse of older people in care homes in Israel identified that 31 per cent of participants without cognitive impairment experienced abuse or mistreatment during the previous year. Harnett and Jonson's (2010) interviews with family members of older people in care settings in Sweden identify the ways in which staff practices undermined the core self of their relative; thereby constituting mistreatment in the opinions of relatives.

There are many contributors to poor practice. On a macro level, Kelly's (2010b) review of contributors to poor dementia care identified restrictive organisational practices, while Innes (2009) identified poor pay and the low status of carework as contributing to a demoralised and poorly performing workforce. Schneider *et al.'s* (2010) study of careworkers' roles in three hospital wards for people with dementia in a UK region identified key organisational issues including insufficient staffing levels, limited opportunities for training and staff development and poor communication about change as contributing to careworkers' stress. Twigg *et al.* (2011) identified the difficulties of co-ordinating spatial and temporal demands within capitalist economic forces and this is particularly evident when such demands require standardising bodily needs and workforce allocation (Cohen 2011). On a micro level, that is at the level of practice, Kelly and Innes (2012) suggest a lack of emphasis on the human rights of people with dementia.

This paper takes a micro level approach to understanding why poor practice, particularly care carried out on the body, continues, despite national strategies, policies and guidelines promoting a person-centred approach to dementia care (Kitwood 1997; Brooker 2007). It proposes three factors that may contribute to poor

practice. First, it considers how fear of 'the stranger' (Harman 1987), 'differentness' (Myhrvold 2006) and the concept of a zombie (Behuniak 2011) might result in careworkers distancing themselves from those in their care. Second, it considers how Western understandings of identity have contributed to potentially damaging discourse of identity in dementia and how non-recognition of selfhood (Kelly 2007) can lead to poor or abusive practice. Third it recognises the difficulties and potential for distaste of carrying out work on the body (bodywork) on frail, leaky ageing bodies.

In recognition of the difficulty of engaging with a 'stranger' or coping with 'differentness' in the context of bodywork in dementia care, this paper proposes using Sabat's (2002) Selfs 1-3 construct to look for aspects of selfhood that we share with each other, or to 'focus on a common human core' (Myhrvold 2006:127). This might enable practitioners to recognise aspects of themselves in the other and thereby facilitate care, particularly bodywork, that respects dignity and recognises the potential for vulnerability (Vanlaere, Coucke and Gastmans 2010) that we would all experience if in receipt of such care. This paper proposes two interlinking processes for facilitating respectful dementia care:

1) Re-viewing the person as more than a body to be manipulated: identifying commonalities of selfhood.

2) Using commonalities of selfhood to empathically reflect on how the practice of bodywork might be experienced by the person with dementia.

First, a brief description of the ethnographic study and Panorama footage are presented.

The ethnographic study

This paper draws on data from an ethnographic study carried out during 2005-2006 exploring the everyday lives of 14 people with moderate to severe dementia in three locked wards of a UK hospital (Kelly 2007)[ii]. All participants were White British; seven were male and seven were female with an age range of 69 to 88. All gave ongoing consent (Dewing 2002) for the researcher to explore their everyday lives in the wards and during weekly artwork sessions with Occupational Therapy staff. Fieldwork was carried out, one ward at a time, over six months and used multiple methods – observation and conversation, Dementia Care Mapping (Bradford Dementia Group 1997)[iii], video recording participants' activities during the art sessions and keeping extensive fieldnotes to explore the responses of participants with dementia, in terms of their well or ill-being and expressions of self, to different types of interaction they experienced in the wards and the art sessions. See Kelly (2007; 2010a) for details of methodology and methods.

All data deriving from fieldnotes, video recordings and Dementia Care Mapping (DCM) were examined to determine participants' responses to interaction types (whether person-centred or not) in terms of their well or ill-being and their expressions of self. All the fieldnotes and the data from each map were subjected initially to open coding to identify broad themes. Then, following DCM's operational rules (Bradford Dementia Group 1997), interactions or behaviours of staff towards participants were coded into negative and positive interaction types. Participants' behaviours and their responses to interactions were also coded according to whether

they appeared to reflect ill or well-being in relation to expressions of self (see Kelly 2007; 2010a for details of analysis).

The BBC footage

In response to concerns, a family member hid a video camera in the bedroom of the UK care home her mother lived in (BBC 2012). Footage gathered over two nights revealed a woman with dementia being harshly, mockingly washed in her bed, by a male careworker, without care for her dignity, accompanied by repeated inexplicable slaps as she cried out in distress. The final assault occurred when he stood over her at the top of the bed and pulled her under her armpits to the top of the bed, hitting her head off the head of the bed in the process. With one final slap on her bare skin, he left the room. In other scenes, two female careworkers manoeuvred, rolled, pulled and pushed her without speaking to her while she cried out in distress. There appeared to be no recognition of the woman's selfhood. The male careworker was convicted of common assault and jailed for 18 months, the four female careworkers were suspended (BBC 2012).

Taking Morse *et al.'s* (2002) verification strategy to theory development, this footage is included as new data to support Kelly's (2007; 2010a) thesis that non-recognition of selfhood can lead to qualitatively different interactions between ward staff and their patients with dementia and to develop the proposition that, in the absence of any knowledge of the person, (identified as an issue by the Care Commission and Mental Welfare Commission in 2009), careworkers could still, through empathic reflection, engage sensitively with people with dementia by recognising aspects of selfhood that they share in common. First, a discussion of the concept of

differentness might elucidate the apparent distance sometimes put between careworkers and their patients.

Applying 'differentness' to dementia care

Differentness, or the extent to which humans differ from each other, 'refers to such a high degree of distinction that it overshadows what is in common and thereby becomes a threatening strangeness' (Myhrvold 2006: 126). Babad, Birnbaum and Benne (1983) suggest that the basis for understanding others is our own understanding of ourselves. People hold implicit theories about their experiences, their world or their behaviour and project these theories onto others' behaviour or experiences. So long as others' experiences are psychologically similar to ours, some degree of understanding will be achieved, but when others are physically, culturally or psychologically very different, understanding and empathy is impaired. As such, people experience great difficulty in understanding those who are significantly different, whether in colour, physical attributes or in their ideology or culture. There is a parallel to be drawn here with the concept of 'the stranger' (Harman 1987) who exists on the outside of a homogenous group, who does not belong but is there anyway, who is attached yet detached, who is involved but indifferent, whose communicative incompetencies leads to misunderstanding and misinterpretation, who is denied group membership on the basis of his/her contradictions and inadequacies and who subsequently becomes a 'marginal man' (Stonequist 1937). Stonequist (1937: 8) describes his marginal person as one who 'is poised in psychological uncertainty between two or more social worlds…where exclusion removes the individual from a system of group relations'.

While the idea of the marginal person assumes intention to move between cultures, the concept has been generalized to describe groups who do not choose marginality, such as culturally and linguistically diverse communities, homeless people or gypsies. Included in this group could be those with dementia whose existence produces a reflexive crisis for others. There is a deeply rooted resistance by in-groups to those who are perceived as strangers and feared for their strangeness. Fear of the stranger has been based on the fear of contamination, both literal and metaphorical, and has been summed up by Hughes (2002: 572-82) as occurring with the development of modernity, with the quest for purity and order and the 'horror of deviation'. As Hughes (2002: 575) points out 'the project of modernity could not conceive of co-existence with strangers, since this would be co-existence with disorder, with fault and flaw'. The solution has been to 'rehabilitate' or normalise people using techniques aimed at correction and failing this to banish and segregate people both physically and psychologically in order to contain uncertainty and disorder. An extreme representation of dementia is examined by Behuniak (2011), who argues that people with dementia have been constructed as zombies or living dead by scholarly (see Gubrium and Holstein 1999; Cohen and Eisdorfer 1986; Davis 2004 cited above) and popular literature, resulting in them being feared and perceived as disgusting.

Further, Myhrvold (2006: 125) writing in the context of refugees, people with serious mental health illness or people who misuse drugs and/or alcohol states: 'Groups of people who have suffered extensive loss in their life contexts may be threatening for us, as they reflect our own fears, and remind us of our own vulnerability.' This could

also be applied to people with dementia who are frail and in institutional care, who have lost more and are more vulnerable than is bearable to most careworkers.

Identity and selfhood in dementia

Dementia within health care is most often associated with increasing loss – of cognitive and physical abilities, of material goods and possessions and of social and personal identities. Dominant philosophical ways of thinking about the relationship between the mind and body have contributed to such negative and fatalistic assumptions for those diagnosed with dementia. Separation of the mind from the body stretches from the time of Plato in which the body was seen as reason's underside; its negative inverted double (Longhurst 2001), through to Cartesian dualism (Descartes 1640) in which the mind is seen as distinct from and inferior to the body. Until the pioneering work of Sabat and Harré (1992), Kitwood (1997) and Kontos and Naglie (2007) who argued against dominant medical understandings of inevitable decline and loss as a result of dementia, those diagnosed with dementia were assumed to eventually lose their identities or selfhoods and were positioned as 'vegetables' (Gubrium and Holstein 1999) or shells of the person they once were (Cohen and Eisdorfer 1986). Indeed, Davis (2004: 378) talking of the 'violence that dementia does to the substance of the person' calls for relatives to be allowed to mourn the loss of the person in the final stages of the condition. Kontos and Naglie (2007), arguing for the consequences of such understandings for practice, propose that 'assuming a loss of selfhood with advanced dementia implies that there is no affront to human dignity in treating those who are cognitively impaired as though they are unable to experience humiliation' (Kontos and Naglie 2007: 551). Therefore,

following this logic, there is no need to consider how a person's dignity can be maintained during practice.

Arguing against such dominant assumptions of loss of self as dementia progresses, Sabat and his colleagues (Sabat and Harré 1992; Sabat and Collins 1999) developed the Selfs 1-3 construct to illustrate three discursive aspects of Self, as described below.

Self 1 is the Self which expresses first person indexicals, for example 'I', 'me', 'myself', 'mine'. This aspect of Self reflects the fact that each person has one single point of view in the world. Through the use of visual and verbal first person indexicals, we take responsibility for our actions, we locate for others our experiences and feelings and tell stories about ourselves. Sabat (2002) suggests that Self 1 remains largely intact in people with dementia even with severe cognitive decline.

Self 2 comprises one's physical, mental or emotional characteristics and attributes, and also one's beliefs and desires about these characteristics and attributes. Sabat (2002) suggests that Self 2 remains largely intact with cognitive decline, although it is vulnerable when others view difficulties caused by dementia as being attributable to the person rather than the condition.

Self 3 is the publicly presented aspect of ourselves: the roles we take on and the appropriateness with which we behave in social situations. Self 3 is constructed,

sustained, nurtured or changed through interaction with others and is therefore more vulnerable to damage than Selfs 1 and 2.

Although there are limitations with this construct in that it takes a Western focus, it does not identify a spiritual Self and its three-fold notion of selfhood under-represents how, through dress, adornment, surgical alteration or digital technology we choose to represent, hide or change aspects of ourselves, its strength lies in its operationalisation of identity in people with dementia; until relatively recently, under-acknowledged in dementia theory and practice. Kelly (2010a) has developed Sabat's (2002; 2006) work to argue for the need to recognise and support Selfs 1-3 in interaction and illustrates both the positive and negative consequences for practice and the person with dementia when selfhood is recognised and supported, or not, within interaction.

Bodywork

Bodywork involves working directly on the bodies of others – touching, manipulating and assessing them; thus the body becomes the object of others' attentions (Twigg 2000). Bodywork in carework is often dirty work and, particularly in the context of older people, it deals with negativities of the body, with fluids, smells and excretions. It is hidden from the sensibilities of others and is seen as distasteful, low status and demeaning. Moreover caring for ageing bodies means confronting one's own ageing (Twigg 2000). Coping with bodywork often involves distancing oneself either emotionally or physically, thus the body is further objectified (Twigg 2006).

Different professions engage in different types of bodywork, with some being viewed as essentially therapeutic rather than to achieve an outcome such as cleanliness. For example, Coe and Anthony (2005) discuss the use of therapeutic massage and complementary medicine for people with cancer and report on empirical findings of benefits, contraindications or risks to the patient with this type of bodywork. Hogg and Warne (2010) discuss how non-medical workers (i.e. a hairdresser, beautician, priest and bartender) conceptualise mental health and illness and how they engage in emotional labour (Hochschild 1983) as part of their work. While not specifically referring to bodywork, Hogg and Warne's (2010) accounts of the emotional labour engaged in by a beautician and hairdresser reveal the extent to which they listen to and engage with their clients, the power of enabling people to 'open up' and the high level of communication and interpersonal skills required to facilitate such work. Gale (2011) in a discussion of bodywork, in the context of student homeopath and osteopath learning, notes the distinction between how these professionals negotiate access to the bodies of others in contrast to the way access is more often granted to the medical profession.

Nursing and carework inevitably involves working on the bodies of others, although there is a hierarchy of work, with those higher up in their field (managers, consultant practitioners) working less on the body than those lower down, for example nursing aides or student nurses (Twigg 2000, 2006; Schneider *et al.* 2010). Indeed, Twigg (2000) suggests that the status work in nursing – management, education and research, involves no work on bodies at all. Discourse on the practices of nursing touch in bodywork is scant; practices 'remain in a zone of silence' (Twigg 2000: 141)

and as a result care workers receive little help or guidance on such practice, unless it is through peer instruction (Schneider *et al.* 2010).

Twigg (2000: 145) suggests that 'fundamentally, carework is 'dirty work' because it deals with aspects of life that society, especially modern secular society with its ethics of material success and its emphasis on youth and glamour, does not want to think about: decay, dirt, death, decline, failure. Careworkers manage these aspects of life on behalf of the wider society, ensuring they remain hidden, tidied away into the obscurity of institutions or private homes.'

Bodywork in dementia care

As dementia progresses, so too does the level of physical and bodily care required by the person. Bodywork is carried out in hospitals, care homes or in the community. Here, increasing frailty and incapacity demands more and more input in terms of the level of bodywork carried out; until at the end all aspects of physical functioning ceases and the body requires total care. Here, bodywork, which is already laden with negativities and distancing coping strategies (Twigg 2000) and feelings of disgust (Widding Isaksen 2002) reduces the person to an object to 'be done to'. To 'be done to' implies lack of consent, possible coercion, objectifying actions and possible resistance. Here from my fieldnotes is an example of 'being done to', with negative consequences for both the participant and careworker. A careworker approaches one of the men...

> *... with a tissue to clean his face. No warning. Edward jumps, hits out defensively with his hands. The careworker talks loudly and crossly 'You've*

got food on your face, you need to get it cleaned' and she tries again. Edward

becomes angry 'no no' and he tries to hit out at her. The careworker shouts at

him 'do it yourself then', and throws the tissue at him.

In this example, the careworker's lack of recognition of Self 1: a normal response to a perceived threat resulted in a transactional (Sameroff and MacKenzie 2003) process of interaction in which there is escalation of aggression from both parties, with negative consequences for both. However, even an essentially therapeutic encounter can be fraught with misunderstanding, and this is particularly the case when there is insufficient communication between parties or knowledge of the person with dementia. Here from my fieldnotes is an example of what should have been a therapeutic experience of bodywork – having one's hair washed and set. However, because of the careworker's lack of recognition or knowledge of Nora's Self 2 (how she preferred her hair to be parted) and lack of empathy as to how it felt to Nora to see herself with a different parting, the encounter causes her distress:

I went to find Nora. She was just having her hair back combed and sprayed.

Nora reminded the careworker that she liked her parting to go from right to

left (but it was lying the other way). The careworker scolded her, probably in

jest, that Nora should have told her earlier how she wanted her parting to go.

'Oh, I forgot to', she said in a dismayed voice. The careworker made some

attempt to change the parting but only half-heartedly. Nora knew that her hair

was different. After the careworker had gone she pulled at it to make it right. I

showed her the mirror and she said 'it doesn't look very great'. She knew how

it should be, how she had always liked it, and now it was wrong. She pulled at

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it, tried to make it lie the way she wanted, for over five minutes with little

success, for it had been so heavily sprayed. She frowned at herself, becoming

more and more disgruntled. In the end she stopped. 'I'm going home now'.

Bodywork that involves dealing with fluids and excretions is seen as distasteful, low status and demeaning (Twigg 2000) and carers may engage in hurried care when encountering fluids and excretions to minimise their distaste. For people with dementia who need increasing communicative support, this can result in an unsatisfactory encounter, as this fieldnote illustrates:

Peter has a runny nose. A careworker goes over to him with a tissue in her

hand 'Peter, wipe your nose'. She hands him the tissue and walks away,

screwing up her face, saying 'That makes me baulk' (expression of distaste)*.*

Peter stands looking at the tissue.

The above extracts exemplify Kontos and Naglie's (2007: 550) proposition that people with dementia can be reduced to 'dehumanised units of work' if selfhood is not recognised in interaction or care work. In the ethnographic study, incidents where patients' dignity (Selfs 1 and 3) was violated were common, even in public areas, and the negative consequences were clear. For example Kelly's (2010b) observation of a patient lying on the sitting room floor for one and a half hours before the ward staff attended to him is a clear example of practice where dignity was not a consideration. Similarly, in this fieldnote below, there is little consideration of maintaining dignity during the encounter:

A care assistant comes out from a toilet up the corridor and she is pulling Kevin with her. Kevin is struggling to walk and the care assistant is struggling to pull him along. She manages to manoeuvre him into a chair in the corridor. Kevin is upset and rattled and looks around him crossly… he looks at the care assistant and mutters crossly.

Here, non-recognition of selfhood resulted in outpacing (Kitwood 1997) and contributed to Kevin's ill-being.

Twigg (2000:180) notes that 'the power dynamics of bathing are inherently unequal. One person, strong and able, stands above and over another who is frail and physically vulnerable, forced to rely on their strength and good will. The client is stripped of their clothes, whilst the bathing attendant retains theirs. Being naked in the face of someone who is not, contains a powerful dynamic of domination and vulnerability...' In the BBC footage, the woman's cries of distress are clear indicators of the harm being done to her as her dignity, safety and human rights are violated. Yet, it appears the careworkers were oblivious to the woman's vulnerability and oblivious to how their actions might feel to her. As Myhrvold (2006: 127) suggests when a person is constructed as different, as was the case here (gender, ethnicity, age, cognitive ability, power, control), 'empathy, which seems to depend on a person being able to identify with the other, is put at risk'. Sabat's (2006) work on retention of implicit memory, even with severe cognitive decline, is relevant here and is an important reminder of the lasting harm that can be done when carers are disrespectful, unkind or abusive when engaging in bodywork.

In contrast to the type of bodywork that occurs in the absence of recognition of selfhood, this fieldnote illustrates the positive encounters that can occur when selfhood is recognised. For example:

> *Nora has her nails done. She agrees with the manicurist that she thinks pink is a nice colour. When her nails are done she admires them, waves them around in a light hearted way. She shows them off to us and is in playful mood.*

Here, Nora is expressing Self 2 in a positive manner: her pride in her characteristic of having polished pink finger nails. However, there was minimal observation of positive experiences of bodywork[iv] in the ethnographic study and no observation of positive experiences in the BBC (2012) programme. This is not to say positive experiences of bodywork do not occur, but to highlight that such work, with its potential for distaste, objectification and consequent poor or abusive practice requires scrutiny in an attempt to understand and remedy its causes.

At a micro level, my ethnographic findings and repeated observations of the BBC (2012) footage suggest that careworkers did not fully recognise the selfhoods of their patients. This is a fundamental barrier to carrying out care that is respectful and could go some way towards explaining the range of abusive and damaging practices described in this paper. In the final sections of this paper, I will suggest a focus on the commonalities of selfhood along with empathic reflection as a way of facilitating respectful care. Finally, I will suggest some practice and research implications arising from this paper.

Identifying commonalities of selfhood

Morse *et al.* (2002:18) propose that rigour in qualitative enquiry can be ensured through the verification strategies of using new data to reconfirm emerging ideas in existing data and of moving 'with deliberation' between a micro perspective of the data and a macro perspective of theory. Using the example of some of the television footage, I will use these strategies to move theory forward by illustrating how, even though I do not know the woman featured, I can recognise aspects of her selfhood that I too would feel if I encountered the same situations; thus I can identify with her commonality of selfhood.

The first thing I see is fear on her face as her chair is moved backwards without warning by two careworkers standing in front of her and pushing it. Here she expresses Self 1: fear, as her location in space suddenly shifts. Then, as she is lifted under her arm pits by the two careworkers onto the bed, her cries of distress indicate either fear (Self 1) or pain (Self 2), or both. She is then swung into a lying position and again cries out either in fear (Self 1) or pain (Self 2), or both. When she can, she tries to make eye contact with the careworkers but is unsuccessful. Here she expresses Self 3: a social being. When two female careworkers approach her bed in the early hours of the morning and try to pull the sheet off her, she resists by holding on to it. Here she could be expressing Self 1: a desire to protect herself or Self 3: a desire to maintain her dignity in the face of two strangers who have woken her up suddenly. As they wash her, without talking to her, she hits out in defence (Self 1), but is slapped by a careworker. When the male careworker approaches her in the bed with the intention of washing her, her cries of distress are clear and she cries out for him to stop. Again she expresses Self 1 – an attempt to protect herself. Her cries

of distress as the careworker roughly washes her intimate areas might also be an expression of Self 3 – an old woman wishing to maintain her dignity.

Empathic reflection

I will now engage in reflection on these experiences of bodywork, using the commonalities of selfhood I have identified: fear, pain, self protection, attempts to maintain her dignity and attempts to engage socially. Even though I know nothing about her, I can empathise with her fear at being handled roughly, without warning or explanation and with her attempts to make eye contact with the two female careworkers – perhaps seeking solidarity with them as fellow women. I jump in horror as she is hit in the face and bare limbs by the male careworker, just as she jumps in shock and pain; therefore I empathise with her assault. I can empathise with her attempts to resist her bed sheet being pulled from her without warning and her attempts to resist the indignity of being pushed and pulled by the careworkers as if she was a sack of potatoes or a lump of meat.

At its simplest, empathy in care work requires being sensitive to patients' sense of vulnerability (Vanlaere, Coucke and Gastmans 2010). Analysis of outcomes of programmes designed to teach empathy to nursing students indicate that experiential learning, where students engage in role play to experience what it might be like to be their patient, showed the most promise in improving empathy of students (Brunero, Lamont and Coates 2010). Vanlaere, Coucke and Gastmans (2010) describe a experiential approach in Belgium called a care-ethics lab in which nurses and student nurses spend two days and one night in a simulated care home; each taking either the role of patient or nurse for the duration. Ethical reflection

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following this period prompts participants to share what the simulation felt like and to develop working points to improve their own practice. Further reflection sessions are aimed at consolidating their learning. This type of approach, in conjunction with recognising commonalities of selfhood, should be incorporated into training those, at all levels, who work with people with dementia.

Conclusions and implications

Despite legislation aimed at protecting their interests and well-being (Scottish Parliament 2000; Office of Public Sector Information 2005) and a focus on upholding their human rights (Home Office 1998; European Convention on Human Rights 2003), people with dementia in institutional care, nationally and internationally, continue to experience abusive or neglectful practice. This paper has drawn on ethnographic fieldnotes and description of footage from a BBC (2012) documentary to explore the nature of bodywork on frail people with dementia in institutional care. It has identified multiple factors for poor practice from micro to macro level, including at the micro level insufficient knowledge of the person with dementia (Care Commission and Mental Welfare Commission 2009), insufficient knowledge of what constitutes good practice and the use of distancing coping strategies when engaging in bodywork that is distasteful (Widding Isaksen 2002). At the macro level are structural and organisational factors of insufficient staffing levels (Schneider *et al.* 2010), poor pay and low status of carework (Innes 2009) and the squeezing of care provision into a capitalist framework (Twigg *et al.* 2011). To understand at a micro level why poor practice persists, the paper has explored some of the complexities of engaging in bodywork and identified the concept of 'differentness (Myhrvold 2006), which, along with using distancing coping strategies to work that is often distasteful

may hinder careworkers' ability to empathise, or be sensitive to another's vulnerability (Vanlaere, Coucke and Gastmans 2010), and therefore their ability to engage in bodywork that is respectful and gentle.

In the absence of a 'quick fix' to organisational and structural constraints and in an attempt to move person-centred theorising beyond intangible, uncertain and problematic ideals (Innes 2009), this paper has followed Morse *et al.'s* (2002) verification strategy and analysed the BBC (2012) footage with reference to Sabat's (2002) Selfs 1-3 to develop the proposition that, in the absence of any knowledge of the person, careworkers could still, through empathic reflection, engage sensitively with people with dementia by recognising aspects of selfhood that they share in common. This approach is particularly relevant for agency or new staff, who may not know their patients to the extent required to respect individuality, or know their likes or wishes, or for people with dementia who do not have their life stories or preferences documented. The absence of such knowledge should no longer be a barrier to carrying out respectful care if, as proposed, careworkers look for aspects of self they share in common with their patients.

This proposition, while drawing on international literature, is developed through small scale, in depth examination of practice in a UK context, and while it would be useful to test it for applicability in different populations, cultures and diverse care settings, its generalisabiilty is inherent in the idea that as social, physical beings we have much in common. It is, however, important that assumptions of commonality do not de-sensitise careworkers to people's individuality or their diversity: their different

cultures, religions, backgrounds, experiences or needs; the challenge is to recognise commonality while acknowledging individuality and diversity.

Innes (2009: 48), in her critique of a person-centred approach suggests 'person-centred ideals may be implemented some of the time for some of the people, but for some of the time and some of the people they won't be.' If this is the case even for some care settings, the alternative approach described in this paper could fill the theory/practice gap. For, regardless of how much or how little careworkers know the person with dementia (and this becomes more difficult with increasing cognitive decline and with a transient workforce), respectful bodywork in dementia care could be achieved through encouraging them to see beyond the distasteful nature of their work and the perceived differentness of their patients to working to identify with aspects of their patients' selfhood that are common to them (whether it be the commonality of having a body, sharing gender, sharing roles of being someone's son or daughter, the commonality of experiencing pain or fear, or needing to have social contact) and supporting them to engage in empathic reflection on how their practice might nurture or damage their patients' well-being. Re-viewing and identifying with the person's commonality of selfhood while engaging in empathic reflection could transform bodywork from a task that is distasteful to the careworker to one where respectful care dignifies both the careworker and the care recipient.

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[i] All participants' names are pseudonyms.

[ii] Ethical approval for the study was granted by the multi-Centre Research Ethics Committee (Scotland), the NHS Local Research Ethics Committee and the Research Ethics Committee of the University's Department of Nursing and Midwifery.

[iii] DCM is an observational tool which evaluates the impact of care practices on the well-being of people with dementia in formal care settings. Its aim is to qualitatively and quantitatively measure how person-centred philosophy is applied in care environments and experienced by those with dementia.

[iv] All observations in the ethnographic study were carried out in public spaces, therefore only the precursors to and consequences of intimate bodywork were observed.