Introduction: Existing research into dementia care shows that it is often marked by a failure to consider the management of appearance as anything other than a disaggregated set of care tasks (Cohen-Manfield et al., 2006). There is an overwhelming assumption in policy and practice that the work of maintaining a person’s appearance can be easily assumed by another, often to be subsumed within the daily task-oriented, time-pressured routines of care provision (Cohen, 2011, Greener, 2011). Guidelines for good practice in dementia care largely overlook ‘body work’ (Twigg, Wolkowitz, Cohen, & Nettleton, 2011) in which the management of appearance is embedded (e.g. NICE-SCIE, 2007), the implication being that this is unskilled work for which little or no training is required. Furthermore, of the still limited discussion of appearance in dementia studies the voices of people with dementia have until now been missing (Ward & Campbell, 2013a). In this paper we present findings from a study that provided an opportunity to open up questions about appearance directly with people with dementia and to explore the meanings it holds.

We report on a set of interviews undertaken as part of a larger study investigating appearance and the work of managing it in dementia care. As the name implies, the Hair and Care project, a 28-month ESRC (Economic and Social Research Council) funded study, has focused particularly upon hair care and stylization both by and for people with dementia, across different types of care setting. In order to contextualise the day-to-day routines and hair-related practices associated with life in/with care, we conducted a series of ‘appearance biographies’. This method allows for a range of topics to be considered about appearance throughout the life course and, as such, acts as a conduit for reminiscence and life story work. Discussions with people with dementia and their careers were stimulated using family photographs and other visual media. The rationale for the study stems from recognition of the limited attention given to appearance in the context of living with dementia to date.

Background: A key question posed by this paper – and by the Hair and Care study as a whole – is whether appearance and the work invested in it are legitimate considerations for dementia care policy and practice. Supporting people to maintain their appearance is an everyday feature of nursing and social care. So, how should we make sense of this work and what significance should we attach to it?

Commentators such as Katz (2011) and Twigg, 2006, Twigg, 2010 argue that the bodies of people with dementia and those in ‘deep’ old age, tend to be perceived as somehow outside of culture. Instead, they are ‘determined by biology and discussed almost entirely in terms of physiological processes requiring expert surveillance’ (Pickard, 2013, p.8). If this is so, then drawing attention to appearance potentially poses a challenge to how the body is understood and constructed in dementia care. The over-arching argument we develop here is that in order to even begin to appreciate the significance that appearance holds for a person living with dementia we must look beyond the immediacy of the caring encounter to consider a person’s embodied history and the biograph-
Appearance, agency and dementia care

Our interest in appearance belongs with a burgeoning movement in dementia studies concerned with embodiment and corporeality (Kontos & Martin, 2013). In part, this is a response to a perceived failure to fully take account of the body particularly within interactionist perspectives on dementia. Notions of personhood and accompanying models of care have, in the past, been unhelpfully ‘disembodied’ often meaning that the body has remained the exclusive domain of medical science. As a result, much of the debate on dementia has overlooked the embodied dimension to self and identity, and neglected the simple fact that our bodies are the basis on which we engage with the world. In short, we have underplayed the role of the body in the agency, self-expression and relationships of people with dementia. The idea that the bodies of people with dementia may be a source of capital has been almost unthinkable, according to both interactionist and biomedical perspectives (as an illustration see Sabat, 2008).

Existing research on appearance and dementia is limited, and often an adjunct to investigations of care, with much evidence originating from institutionalised settings. In a recent overview of this research Ward and Campbell (2013a) spotlight the question of authorship in relation to managing appearances in care, citing evidence that settings such as care homes can appropriate the appearance of individuals through the imposition of generalised standards of presentation intended to signify the quality of care provided (Lee-Treweek, 1994, Lee-Treweek, 1997). Twigg (2010) and Topo and Iltnen-Tahkavuori (2010) further reveal how organisational systems such as the boil–wash communal laundry can dictate the nature of the clothes people are able to wear, and the types of fabric from which they are made, but also lead to clothes being lost or passed to other residents.Appearances are thereby shaped both by the social and material environment, eroding the choice and agency of the individual. In the case of clothing deliberately intended to restrict certain forms of behaviour, such as disrobing, the regulatory impulses of care providers over-ride any potential for self-authorship of appearance by the individual (Iltnen-Tahkavuori, Wikberg, & Topo, 2012).

But appearance and the work of managing it can also be supportive of self and identity in care. Twigg (2010) and Twigg and Buse (2013) argue that items of clothing can be important biographical objects, carrying memories and reminders of others, as well as having valuable sensory qualities through texture, colours and smell. In developing a theory of embodied selfhood, Kontos (2006) singles out sometimes fleeting moments where people with dementia attend to their appearance as evidence of an enduring selfhood. Appearance practices, Kontos suggests, reflect deeply ingrained habits borne out of life-long processes of socialisation and enculturation. Paying attention to care-based hair salons, Ward and Campbell (2013a) point to the social, sensory and embodied practices of the salon as meaningful to people with dementia, rooted as they are in long-standing gendered traditions of visits to the salon or barbers across the life course, while playing a role in the on-going negotiation of ageing identities.

The management of appearance has been shown to carry particular significance to both formal and informal carers. Care workers can use appearance work as an expression of the bond they have with individual residents (Ward & Holland, 2011), and to protect the person with dementia from stigmatising responses in public environments (Reed-Danahay, 2001). Families, relatives and friends also value efforts to co-manage the appearance of their loved one following admission to care (Nolan, Grant, & Keady, 2002) often this...
stems from recognition that maintaining appearances can support a degree of biographical continuity for that individual at an embodied level (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008). Tensions can however arise between this desire for continuity and more immediate concerns for comfort and practicality on the part of care providers (Ward et al., 2008). This existing research demonstrates that appearances can be a highly sensitive and politicised domain in dementia care but also serve as a nexus for processes of selfhood and identification.

The Hair and Care project

The wider study in which the appearance biographies were undertaken was carried out in a designated region of the north-west of England. A qualitatively-led mix of methods included mapping of the provision of care-based hairdressing across the area of the study, as well as sensitising discussion groups and more in-depth interviews with stakeholders and key informants. Participant observation (and observant participation) was used over a period of eight months in a series of care-based salons in hospitals, day centres and care homes as well as visits to people at home. During this period we conducted filmed conversations with workers and their clients (a more detailed account of the methods used is offered in Ward & Campbell, 2013a).

From the outset, it was our intention to involve people with dementia in the project irrespective of the severity of their condition. Hence, ethical approval was obtained from an approved NHS Research Ethics Committee with knowledge of the Mental Capacity Act (2005), a process we have also described elsewhere (see Ward & Campbell, 2013b).

In the final stage of fieldwork we recruited 12 people with dementia to participate in ‘appearance biographies’. This paper considers the content and process of these interviews and the implications for policy and practice. The names used throughout this article are pseudonyms.

Analysis: Narrative approaches are now an established feature within dementia care practice and research (Williams & Keady, 2006), often underpinned by recognition of how people with dementia have been silenced or ‘narratively dispossessed’ by the dominant medical model of dementia (Baldwin, 2006). In the context of this study, we understand the performance of narratives as opportunities for the on-going constitution of self. People use narrative to interpret and organise their experience through the process of storying their lives (Roach, Keady, Bee, & Williams, 2013). Like Plummer (2001) we see narratives as creating a bridge between personal biographies and wider cultural histories and social conditions. The narratives of appearance management constructed in the course of the interviews were therefore the primary focus of our analysis.

We began with thematic analysis of each interview transcript carried out by both researchers (RW & SC) and then compared and synthesised our headings before seeking to identify themes and patterns across the data as a whole (Riessman, 2008). We then concentrated more closely upon illustrative and particularly rich narratives, including the jointly achieved story-telling that was a feature of many of the interviews. We considered each narrative as a context that gave meaning to the events, practices and short stories enfolded within them (Phoenix, Smith, & Sparkes, 2010).

In the account that follows we draw out key themes from the interviews and consider what they reveal about the management of appearance over time and the meaning it holds for people in the present.

Alzheimer’s disease (AD) is the progressive mental deterioration of the brain overtime most usually seen
in adults over the age of 65. Past studies have found that factors that increase amyloid beta production in the brain or make it difficult to remove amyloid beta plaques are risk factors or possible causes of AD. These factors include β-secretase, an amyloid precursor protein cleaving enzyme. B-secretase is believed to be responsible for initiating the amyloid beta protein formations. Maysin is a flavone C-glycoside from corn silks and maize with past studies having shown Maysin from Centipedegrass (CG) to be protective against the formation of amyloid beta plaque build-up and tangles as well as helping to counteract oxidative stress. Isoorientin 2-O-rhamnoside (IR) is a flavonoid compound similar to maysin also found in CG. Little work in the past has been done with IR compounds and discovering its use as an anti-AD measure. We hypothesis that IR flavonoid compounds can exert anti-AD properties such as an inhibitory of amyloid beta oligomerization process and the ability to counteract BACE activation. In neuronal PC12 cellular model, inhibitory activity of β-secretase increased in the IR dose-dependent manner. These results could have significant implications on the understanding and prevention of amyloid beta and Alzheimer’s disease progression.

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