'Once I had money in my pocket, I was every colour under the sun': Using 'appearance biographies' to explore the meanings of appearance for people with dementia

Richard Ward a,⁎, Sarah Campbell b, John Keady b

a School of Applied Social Science, University of Stirling, United Kingdom
b School of Nursing, Midwifery and Social Work, University of Manchester, United Kingdom

Abstract
Appearance and the work invested in it by and for people with dementia are a neglected issue within dementia studies. In policy and practice there exists an assumption that the role of supporting a person to manage their appearance is easily assumed by another within caring encounters, only to be subsumed within the daily task-oriented provision of care. This paper reports on interviews conducted as part of the Hair and Care project, which explored questions of appearance and the meanings it holds with people with dementia. The research used 'appearance biographies', a method which allows for a range of topics to be considered about appearance throughout the life course, acting as a conduit for reminiscence and life story work. The paper reports on the key themes and findings from these interviews, discussing them in the context of a wider debate on dementia, self-expression and agency. A key question posed by the authors is whether appearance and the work invested in it are legitimate considerations for dementia care policy and practice. And if so, how should we make sense of this work and what significance should we attach to it? In seeking to answer these questions the authors position the perspectives and experiences of people with dementia as central to their analysis. A narrative framework is suggested as a useful basis on which to understand the work of managing appearance over the life course. The implications for policy and practice are outlined.

© 2014 Elsevier Inc. All rights reserved.

Keywords:
Appearance
Biography
Dementia
Care
Embodiment
Narrative

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-Mansfield 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-pressed 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, 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 biographical and cultural context.

**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, 1997). Twigg (2010) and Topo and Iltanen-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 (Iltanen-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.

The appearance biographies

We interviewed seven women and five men, all of whom were white-British, their relationship histories indicating that all were heterosexual. All but one had grown up in the north-west of England, mainly within working class neighbourhoods. Hence, we make no claims for representativeness based upon this small sample.

While we were certainly interested in peoples ‘hair stories’ the interviews ranged over whatever aspects of appearance management were significant to that individual. People were asked to commence their narratives with memories from childhood and in this way we introduced a loosely chronological format. Most chose to have a supporter present (usually a partner or other family member) and many also decided to introduce photographs from different points in their lives. These images offered a parallel visual narrative to complement the oral accounts provided. Most of the interviews lasted between an hour and an hour and a half, on two occasions we terminated the encounter responding to signs of tiredness and revisited at another time. Each interview was transcribed in full using a ‘play-script’ style.

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 storytelling 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.

Appearance and the life course

The role of appearance in the formation and embodiment of identity

Perhaps unsurprisingly, parents emerged as influential figures in fostering notions of acceptability and respectability with regard to appearance. For instance, we visited Vic and his wife Judith, a married couple in their 70s, and even before the interview had commenced Vic pointed to a pair of his shoes in the corner of the room and related a story of how his mother would shine his shoes for him as a child, holding them up to ask if he could see his face in them (he enacted the vigorous shining of shoes as he related the story). Later in the interview he remarked:

Some people didn’t care what their kids looked like, my mother was just the opposite, and you had to do it, she told me what to do — my shoes had to be cleaned and all that... that was my era.

His wife Judith further elaborated... it used to be regarded as a good personality if you had shiny shoes, if you cleaned your shoes.

Vic’s parents had clearly played an important role in connecting appearance to character and notions of propriety. But, they also influenced his appearance by modelling its upkeep and communicating a sense of what feels right as well as what looks right. Vic went on in his interview to describe his father’s influence on his shaving routines and as he spoke he rubbed his chin with his hand.

- You never see me going out without a shave... I could not under any circumstances go out without... I couldn’t do that

Interviewer — So you’d never let it grow for a day or two and have a bit of growth?

- No, no

Interviewer — Why is that? Why wouldn’t you want to do that?

- Because my dad had me from that day — ‘you’ve done this, you’ve done that, that’s standing up now you better get that right, do that now, get that done’
Interviewer – So it’s partly your dad’s influence a little bit is it?

- ‘Oh aye, when father spoke you didn’t say no. Poor fellow is gone now and he’d say you’ve missed that – come here – how many times must I show you this…’

In talking about their appearance we found that people were less likely to conjure up an image of themselves at a particular point in their lives and more likely to recall the doing of appearance and the different influences upon it. The photographs we referred to further informed an understanding of how appearances were fostered through modelling and resemblance within families. For instance, after noting that her husband appeared with a shirt and tie in almost every photograph, Judith pulled out one image commenting: ‘There you are, there is your dad. Vic and his dad there, but both had ties you see’. Later she chuckled as she recalled ‘I have known Vic ON THE BEACH with our children, with a tie, collar and tie’. In response Vic explained ‘I was one of those if I haven’t got a tie here [reaching up to touch his throat] I was undressed… ‘I couldn’t bear to have this [pointing to his top button] open’. His smart appearance was an embodied link to his father’s sartorial standards but also integral to Vic’s embodied sense of self.

The interviews showed how such early influences were subsequently carried forward over the life course, giving people a sense of connection through time to these formative years. Now in his 70s, and still wearing a shirt and tie, Vic had kept up the careful attention to his shoes throughout his life, the embodied act of shining them (as he re-enacted during interview) bringing to mind his mother’s advice. While the feel of a clean-shaven chin stirred memories of his father’s shaving demonstrations. Vic’s narrative illustrates how the repetitive nature of these practices, unfolding throughout his life, had become a source of continuity for him at an embodied level.

The ‘full-bodied’ way in which memories of appearance were brought to life was a notable feature of the narratives. For instance, one interviewee vividly recalled the warmth of sitting in front of the fire (in a pre-central heating era home) as her mother tied her plaits for school the next day; another laughed as she recounted how the design of a skirt worn in her youth forced her to go ‘knock-kneed’ every time she tried to board a bus. Grimacing, Judith recalled clothes made from synthetic fabrics: ‘I remember wearing a lot of nylon and always getting really hot and sticky, because you didn’t breathe through it did you’. People’s recollections in these interviews were very much of the lived and embodied experience of appearance. They reveal that appearance is about more than just image, it is something that is felt and very much a multi-sensory phenomenon. Rubbing his chin as he spoke of the importance of being clean-shaven, Vic showed that our sense of self is tied to feeling a certain way as much as looking so, over time.

The ‘backstage’ work of appearance

For many of the women we spoke to, the interviews were an occasion to make visible the work they had invested in the appearances of their family throughout their lives. Their narratives included accounts of careful budgeting and shopping for items such as coats or shoes, ‘do-it-yourself’ haircuts and the making and repair of clothing. Fran described the skills involved in recycling her husband’s work shirts:

When the collars were fraying, I would undo all the seams, unpick them all, take the buttons off, wash and press them, and then cut out, I had patterns for shirts for the boys and even my [daughters] had little blue dresses from shirts.

Such labour showed how Fran actively shaped and inhabited the appearances of her family, her own embodied practices becoming inscribed into their bodies. A distinctive culture of consumption and relationship with consumer goods and items such as clothing was outlined. Often, this involved efforts to extend their life. Gwen’s grandson recalled how the skills and appearance practices she had passed on served him well in the military:

In terms of my experience of clothes it comes from my nan who’s sort of make-do and mend, and fix and how to do things, sort of husbandry with clothes if you like… She taught me how to iron a shirt and when I got [into the army] I was one of the few who could actually do it. So it’s not so much the fashion itself, it was more how to take care of your clothes and how to look after them.

Appearance-related labour within households was highly gendered for many of the people we spoke to and very much a situated accomplishment according to socio-economic conditions and local cultures of respectability which people sought to embody through appearance and conduct. But this labour also reaffirmed familial and relationship bonds. For instance, some women spoke of ironing night clothes and bedding in the knowledge of the sensuous pleasure derived from climbing into crisp clean sheets and pyjamas. Such work had less to do with public displays of respectability but revealed a kind of vicarious embodiment that involved anticipating and actively managing the sensory and bodily experiences of loved ones.

Using appearance to uphold continuity and manage change

During the interviews there were occasions when people drew attention to the more idiomatic aspects of their appearance which over time had evolved into appearance signatures. People described their loyalty to a certain perfume or how they would amass collections of a particular item of clothing or accessory. Items of jewellery were sometimes presented to us during interview, in many cases they were rarely or never removed and had become almost absorbed into the body of the wearer as Gwen’s grandson revealed of a necklace he’d bought for her while on holiday:

‘I bought it back and she wore it. She never took it off, for years. Do you remember that? ‘Number One Nana’ as it was called…. It got all crunched up in the end from when she went to sleep and things like that, but 20 years she wore it’.

Mo’s appearance signature was the colour purple. It was, she explained, her family’s colour:
Purple is probably one of my first... is my colour really. It's Mark's colour as well, isn't it, and what have you. And the same with my mum, there's purple...

Interviewer: Where did that come from then do you think? I think it's still to do with Mark really. I've got two brothers, I've got Mark that's died and Glen as well. This signatory colour was a means of memorialising a loved one while reflecting the familial network to which Mo belonged. By wearing the colour purple she could keep the memory of her brother close to her and immediate and in this way she revealed not only the deeply personalised meanings embedded within her appearance but also its inherently relational nature as it functions to express a connection with others over time. Hence, appearance signatures were a way of preserving and maintaining a sense of self, they offered continuity at a subjective and embodied level.

For some of those we spoke to appearance provided a basis for responding to change in their lives and for marking biographical milestones. Lily, a woman in her 70s who lived alone in sheltered accommodation, spoke of how changes to her appearance had heralded new-found freedoms in her life. She described how entry into different life stages (such as the first wage packet) offers differing configurations of constraint and opportunity in terms of appearance. After a childhood defined by other people's choice of clothes she had been able to start making choices for herself albeit still according to tightly defined constraints.

Choice and scope for self-presentation shifted more subtly in the transition from weekday to weekend, and in the context of celebratory events and holidays. This was underlined by the photographs introduced during our discussions. Many were taken to mark occasions, such as parties or family gatherings, and depicted people 'dressed up', adopting sometimes quite formal poses. Lily picked out one image where she and a close friend wore matching dresses on a day out, revealing how appearances could be used to bind people together. Collectively, the images revealed the range of different 'selves' and biographical events that people sought to capture but also signalled for us those which were not recorded or considered suitable for a personal or familial visual inventory, illness being one such example.

Managing appearance in the context of living with dementia

Mo, who was married and in her 60s, had been forced to finish work as a result of early-onset dementia, and described the various effects this had upon the way she looked. Stopping work had led to inactivity and subsequent weight-gain but she had found it difficult to follow a diet — sometimes forgetting to eat altogether but also, as her daughter pointed out, struggling to maintain a regimen:

‘...and looking at calorie contents on things, it’s not always easy, because numbers were one of the first things to go, wasn’t it?’

In other respects Mo had a pragmatic response to living with dementia:

‘Well my hair’s always been very long, and I decided to get it chopped because I felt it was too much for me to do, when I first got my diagnosis and everything. And I just couldn’t be bothered. I mean it was down here, my hair...’
Daughter: ‘You used to have to do more styling of it, didn’t you?’
‘Yeah and I just couldn’t do it. So that’s how I finished up having short hair. But I’m quite happy about it, I’m still happy about it because it’s easier to do it now’

Mo’s ‘hair story’ shows how appearance can be both a reflection of and a vehicle for managing the transition to living with dementia. Whereas a severe haircut might have felt destabilising for some people at a time of such widespread change in their life, for Mo it was an expression of her adaptation to living with the condition. Her account shows how the onset of dementia requires people to negotiate and make allowances for the changes wrought by the condition, sometimes weighing practical considerations against the more symbolic significances of how they present themselves to the world. During interview, people described how dementia could affect regimes of self-care and bodily routines but also suggested that appearance could be an arena for resistance and continuity in the face of change.
For some couples, a joint response to the onset of dementia was a continuation of the way they had worked together over many years and this included an often collaborative approach to managing appearances as Stuart and his wife Deborah revealed:

Interviewer: Have you always bought your own clothes or have other people bought clothes for you?
Stuart: I did up to the time Debs and I got together and after that I have had nothing whatever to do with clothes at all. Debs is in charge. I don’t have anything to do with clothes. When I need something, she thinks I need something, she will go out and...
Deborah: ‘He NEVER thinks he needs anything […] I mean I know his waist size and his leg length and the colours that suit him and what he likes as well… But going back to hair, I used to cut your hair for years didn’t I?’

Having always influenced her partner’s appearance, Deborah had begun to monitor his presentation as a protective measure following the onset of dementia. This response underlined the fundamentally relational nature of Stuart’s appearance and how she saw herself as implicated in it, something she touched upon more explicitly later in our discussion.

And that’s why, when you, you know, even if you say ‘oh I’ve just put this shirt on’, I’ll say well it’s no use it won’t go with, you’ve got black with navy and he’ll say ‘Oh alright’ even if it’s a bit of a fag at least somebody’s caring. And he’ll say ‘Oh I’m only playing with the old chaps at the golf club’, I’ll say ‘well they still know you’re married to me, change your top – doesn’t matter what they think’
Interviewer: So Stuart’s appearance is a reflection on you in some indirect way would you say?
Well, I wouldn’t want people to think I didn’t care how he looks when he went out.

As Deborah’s comments indicate, appearances can be a register of the relationships in which we are embedded. Her efforts to uphold Stuart’s public image show that appearance work is woven into the maintenance of couplehood in the context of living with dementia.

‘I think when it [hair] gets longer and fuzzy looking and he’s got on his gardening tracksuit bottoms and an old t-shirt, which is absolutely fine for the garden — it’s amazing how dishevelled, rightly so for a gardening thing, but add to that something where the clothes aren’t right, you know, that the clothes may be a bit stained or something like that and the shirt’s maybe very old and worn, I think that feeds into the dementia look’

Deborah’s concern over the ‘dementia look’ reflects an awareness of how ageing can lead to rather different readings of our appearance. Laxity over appearance in later life is culturally encoded, often taken as an indicator of vulnerability and incapacity and Deborah’s impulse is to protect her husband from this. Their narrative shows that the process of sustaining a relationship takes place at an embodied level, with collaborative work on appearance being integral to the strategies that couples employ to cope with dementia but it also underlines how significant relationships are both projected from and inscribed into our bodies through the management of appearance.

Discussion: the narrative properties of appearance

In this section we relate the findings from the interviews to a wider debate on dementia, self-expression and agency. We begin by developing the argument that when considered in a biographical context, appearance and the work invested in it can usefully be understood as a form of narrative that unfolds at an embodied level. Our starting point is Baldwin’s (2008) argument for narrative citizenship.

Baldwin (2008) argues that personhood is a performative activity. Selves are constituted through the stories we tell. In other words, narrative is a form of social action (Phoenix et al., 2010) and has transformative potential as we learn about ourselves and the worlds we inhabit through our efforts to organise and compose stories of our lived experience. However, such narrative agency is often denied to people with dementia due to rigid expectations of what constitutes a story and how it must be told. Consequently, Baldwin suggests that to support the agency of people with dementia we should look beyond the spoken and the written to a narrative of self-identity. In the context of living with dementia, Twigg (2010) has similarly argued that clothing can be considered part of an on-going narrative of the self and often hold special status as biographical objects in this respect.

The data gathered for the Hair and Care project further underline the narrative properties of appearance and, in relation to dementia we argue that such an interpretation highlights three important insights. First, it contributes to an emerging recognition of the embodied dimension to biographies, identities and a person’s sense of self. Second, it foregrounds the role of the body and embodied experience in the process of meaning-making. And third, it points to an understanding of the body and personhood as intrinsically relational.

Our interviews showed that bodily sensations and sensory cues often served as a vehicle for memories of appearance and the work of managing it. Embodiment was integral both to the process of remembering and to the memories themselves. Memories were brought to life through recollection of the feel of different aspects of appearance, such as the texture of an item of clothing or the way its design defined movement (see also Twigg, 2010). People described and enacted kinaesthetic memories of particular appearance practices such as shaving or applying make-up; life-long adherence to these practices underlined their significance to a sense of self. For instance, Vic’s insistence that it would feel unbearable to leave his shirt unbuttoned clearly indicated how long-standing appearance-related practices become sedimented over time to create a sense of who we are (Crossley, 2006). A particular configuration of sensations, dispositions and other sensory features thus helps to define us based upon our embodied experience of the world.

Until now, dementia care has been characterised by efforts to measure the bodies and sensory capacities of people with
dementia, often focusing upon how the condition interacts with a loss of sensory acuity (Bakker, 2003; Jones & van der Eerden, 2008). Far less attention has been paid to how people use their bodies and senses to create meaningful worlds (Howes, 2003). The interviews showed that sensory knowing is infused with social significance but in ways that are by no means akin to cognitive forms of understanding. As Howes (2005) points out; ‘a perfume is not the same as a sentence’ (p.3). Instead, the multi-sensory nature of appearance work offers a form of embodied knowing and a basis for meaning-making at a bodily level. Often this process is shaped by cultural norms and a broader communal sensory order that signals social location and belonging. Hence, laundering and ironing, patterns of personal hygiene and the choice of scents and hair products all carry sensory information regarding social identities and group membership, linking the body to a wider social and moral order (Pink, 2009).

The narratives were useful then in showing how people draw upon sensory and embodied experience to construct stories of themselves, but also for the insights offered into the sensory worlds that people inhabit throughout their lives.

Such findings contribute to an emerging recognition of the significance of the body to processes of self-expression and story-telling (Hyden, 2013). As Phoenix et al. (2010) have argued, ‘we not only tell stories about our bodies, but we also tell stories out of and through our bodies, potentially teaching ourselves and others within this process’ (p.3, 2010). Narratives of appearance were a way to bring forth people’s embodied histories (Kontos, 2006). But, we also came to understand how appearance and the work invested in it play a substantive role in narrativising identity and selfhood. Appearance embodies the biographical self, materialising the stories of who we are.

The narratives offered in the course of this study were characterised by a focus upon the doing of appearance and the array of practices involved in managing it over time. We learned of the time, effort and creativity that went into self-presentation and the processes by which these practices were passed on through families and by other influential figures. In developing his notion of ‘reflexive body techniques’ Crossley (2006) similarly focuses upon the importance of the doing of appearance arguing that techniques of body maintenance and modification are significant because they play a central role in the construction of a reflexive sense of self:

Learning to attend to ourselves is learning to posit ourselves for ourselves. It constitutes a specific experience of self. We learn to play the role of another in relationship to ourselves. Indeed, in some cases where we attend to ourselves in these ways we are precisely taking over the role of another, a parent or guardian, who once tended and cared for us in these ways. We do to ourselves what they have done for us at an earlier time and have taught us to do, applying their standards and techniques to ourselves (p. 108)

Crossley’s account of the transmission of body techniques underscores the relational nature of appearance and how it both absorbs and displays the influences of those around us. In describing how he learned to shave and shine his shoes, Vic reveals how the morals and mores of his upbringing have been incorporated into his body to create an experience of who he is, for himself. Similarly, as Gwen’s grandson notes of the skills she has passed onto him for what he calls ‘husbandry with clothes’, she has communicated a set of values in an embodied form, a way of being in the world.

Crossley’s (2006) analysis is helpful to our understanding of appearance management because he underlines the mindful way in which the body works back on itself when people attend to their appearance, our awareness switching back and forth from the body that is worked upon to the body that carries out the work. This framework is relevant to the debate on selfhood and dementia because it focuses upon a person’s own on-going sense of self.

The doing of appearance not only fosters an embodied awareness of self but also provides a basis for preservation and transformation. Hence, even at the micro-level of the work invested in the Friday night ritual of getting ready for going out – such as the careful application of make-up, scents and perfumes, styling of hair and dressing up – the power exists to effect ‘an existential transition from [the] mundane workday mode to the “soiree” self’ (p.108). Managing our appearance is then a form of social action with consequences for how we are perceived and how we see ourselves over time. The many different appearance signatures outlined during the interviews functioned to support the preservation of aspects of self and identity in a deliberate and knowing fashion. Whereas, in actions such as Mo’s cutting of her long hair, a significant biographical transition is both marked and performed.

Appearance thus serves as a site for responding to and negotiating certain tensions according to a person’s situation and social location. In this respect the appearance biographies offered insights into how a person’s body and embodied practices are the locus for intersecting aspects of identity (Mirza, 2013). In her exploration of the relationship of class identities to notions of respectability Skeggs (1997) underlines how, through their conduct and appearance, working class families sought to manifest an elusive respectability that was seen as effortlessly embodied by the middle classes. Hence, Judith’s gentle mocking of her husband for wearing a shirt and tie even when on holiday at the beach, offers a precise and illuminating insight into how men such as Vic negotiated the tensions inherent in working class masculinities around the middle of the twentieth century. The management of appearance is shown to be a form of intersectional practice, a response to the way different aspects of identity converge at the level of the body, underlining how appearances form a bridge between personal biographies and wider cultural histories.

Focusing their attention upon shoes Hockey, Dilley, Robinson, and Sherlock (2013a) highlight the ‘mundane transitions’ made when we change from one type of footwear to another, they note the playful way we can interrupt the temporalities of our life course either accelerating or deferring future age-based identities through our choice of shoes (Hockey, Dilley, Robinson, & Sherlock, 2013b). As items of material culture shoes are linked to the formation of memory, intimately caught up with life events (Hallam & Hockey, 2001). Our interviews further highlighted how the embodied practices through which we engage with such biographical ‘objects’ – whether shining shoes, getting dressed or styling hair – were also integral to memory and the performance of age-based identities. Certain practices, when
kept up throughout the life course, can condense time bringing people closer to their childhood or to relationships from earlier points in their life.

We learned that appearances can serve as a register of specific, significant relationships. The interviews showed that the work invested in appearance can be a way of reaching out to someone, affirming a connection, but is also a way of enfolding that person’s influence into our bodies by orienting ourselves to certain styles, capacities, aspirations, techniques and habits (Ahmed, 2006). Hence, Mo’s loyalty to the colour purple was oriented to her family and her brother in particular, while Vic’s shoe-care embodied a connection to his parents and early formative experiences at home. These insights underlined the relational nature of appearance and of our bodies, supporting recent arguments for an understanding of personhood as transactive and intercorporeal (Jenkins, 2013; Zeiler, 2013).

Following the onset of dementia, the significance of managing appearance in the context of a relationship was underlined. For example, Stuart’s appearance was both a result of he and Deborah ‘working together’ (Keady & Nolan, 2003) and a symbol of their bond. As Hellström, Nolan, and Lundh (2007) point out, such a collaborative approach can often be a continuation of ‘well-established ways of being in a loving and trusting relationship’ (p.392). In this respect, appearance was shown to be a focus for a joint response to dementia — an embodied form of co-construction or ‘scaffolding’ (Hyden, 2011).

In his model of narrative citizenship, Baldwin (2008) suggests that people with dementia can be supported through practices of joint authorship in which the narrative process becomes a collaborative endeavour. The interviews we conducted offered clear examples of this as participants worked together to tell their story but this process was mirrored at an intercorporeal level in the joint management of appearance. Hence, appearances themselves were shown to be relationally fostered, through on-going processes of transmission, collaboration and sometimes hidden forms of labour and care. This insight into the inherently relational nature of appearance points, we believe to a more fruitful way of understanding the nature of the support offered to people with dementia to manage their appearance. As Baldwin suggests, we can understand this as a form of joint-authorship, in a context where appearance is recognised as a narrative of self-identity.

Baldwin’s (2008) framework for tracing the narrative agency of a person with dementia further includes paying attention to their contributions to the narratives of others. This perspective also lends itself to our notion of appearance as narrative. In addition to the transactive nature of appearance management in couples, we also saw how people invested in the appearances of others, for example in the way that Gwen passed on her skills and values to her grandson. A major contribution was also outlined, particularly by the wives and mothers we interviewed, through the labour invested in the appearances of their family, from the intricate tasks of recycling clothing to the weekly and labour-intensive regime of laundering, ironing and repair.

Looking ahead: the implications for practice

We have found that appearance is a way of doing things as much as an end in itself. A narrative approach has led us not so much to the meanings that appearance holds for people, but more to an understanding of how people reveal themselves through their appearance and the processes of managing it.

The interviews showed that the subjective significance to appearances were often not visible or easily discerned. For instance, the way in which wearing a certain colour might keep alive a memory, be a response to loss, or a source of continuity and a link to an earlier self is something we can only discover through such narratives as those examined here. Hence, appearance biographies could serve an important role in the provision of care.

The interviews reveal that body work has a potentially vital role to play in upholding an embodied dimension to biographical continuity. We found that certain bodily dispositions, practices and configurations of sensations and sensory cues are as integral to someone’s life story as written or spoken narratives or collections of objects and images. We are who we are on the basis of how we do things and the way we feel as we’re doing them as much as what we do and why (Bourdieu, 1977; Pink, 2009). Knowing for instance that the feel of a clean-shaven chin has long contributed to a sense of self for someone in care and how by rubbing his chin that person can ignite memories of parental influences holds important implications both for the status and meanings that we apply to body work in dementia care.

The key challenge for care to emerge from this study is to find ways to enable people with dementia to continue to do things with and through their appearance, maintaining a feeling of who they are as well as a desired look or image. An embodied dimension to upholding dignity through care emerges clearly when we examine people’s embodied histories, underlining the moral dimension to care work. Above all, these interviews offer substance to the claim that appearance is far from incidental to the lives of people with dementia. It lies at the heart of what we have come to understand as personhood and is a significant basis for telling an on-going story of who we are.

Funding acknowledgement

This research has been funded by the Economic and Social Research Council (grant number: RES-061-25-0484).

Acknowledgements

The authors wish to thank the people with dementia and their carers who participated in these interviews and the staff of the host organisations for their support throughout the project. We would also like to thank the two reviewers for their positive and helpful comments.

References


