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Article:

Twigg, J and Buse, CE (2013) Dress, dementia and the embodiment of identity. *Dementia*, 12 (3). 326 - 336. ISSN 1471-3012

<https://doi.org/10.1177/1471301213476504>

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Dress, dementia and the embodiment of identity

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Abstract

The article explores the significance of dress in the embodied experience of dementia, exploring questions of identity, memory and relationship. It suggests that clothing and dress are important in the analysis of the day-to-day experiences of people with dementia, giving access to dimensions of selfhood often ignored in over-cognitive accounts of being. As a result clothing and dress can be significant to the provision of person-centred dementia care. These arguments are explored through ideas of embodied identity, the materialisation of memories, and the maintenance, or otherwise, of appearance in care. The article forms part of the background to an ESRC funded empirical study exploring the role of clothing and dress in the everyday lives of people with dementia, living at home or in care homes, and of their relatives.

Keywords

Clothing, dress, dementia, embodiment, identity

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Introduction

The last decade has witnessed the emergence of a new paradigm for dementia studies that has emphasised the continuing personhood of the individual with dementia. Drawing on a range of influences – philosophical, ethical, sociological, and practice based – this has challenged the dominant narrative in terms of the erosion of the self through cognitive decline, substituting a broader based, fuller account of being in which embodiment forms a central part (Beard, 2004; Downs, 1997; Harris, 2002; Hughes, Louw, & Sabat, 2006; Kitwood, 1993, 1997; Kontos, 2004; O'Connor et al., 2007; Sabat, 2002; Wilkinson, 2002).

Personhood encompasses a number of elements: personal and relational, existential and moral. Kontos (2003, 2004, 2006) in particular has argued, drawing on Merleau-Ponty and Bourdieu, that we need to grasp the ways in which personhood is embodied, existing at a pre-reflexive level, in which the body both provides the corporeal foundation of the sense of being-in-the-world, and is the bearer of distinctive socio-cultural habitus. This concept incorporates primordial as well as socio-cultural aspects of embodied personhood (Kontos, 2004, p. 837), and it survives even when the higher cognitive functions, normally associated with the self, are eroded. For Kitwood and others of the interactionist school, personhood needs to be understood as something that is social and collective, constructed and enduring at the level of social relations as much as an inner cognitive core. This agenda highlights the ways in which depersonalising social interactions can erode personhood and identity as much as cognitive impairment so that the aim of care should be to establish a framework in which interactions are benign and endorsing, rather than malignant and erosive (Kitwood, 1993, 1997; Kontos & Naglie, 2007; Sabat, 2005).

This shift in understanding has helped make visible the potential role of clothing and dress in the lives and experiences of people with dementia. Dress is traditionally theorised in terms of

agency and expressivity, and located in the world of fashion and consumption. People with dementia are normally excluded from such realms. But in this article, and in an earlier one (Twigg, 2010), we argue that dress is indeed relevant to the lives and well being of people with dementia. Clothes lie at the interface between the body and its social presentation. They signify to the wider world who and what the person is; and in doing so have the capacity to act back on that individual endorsing their sense of identity at a directly embodied level. They can thus play a significant part in the maintenance, or otherwise, of embodied personhood.

This paper draws together literature on clothing, identity, biography and everyday social interactions in order to expand current discussion concerning the embodied identity and personhood of people with dementia. It begins by considering sociological and fashion theory on clothing and embodied social identity, exploring its relevance to people with dementia. This is followed by an exploration of work on material culture, clothing and biography, and its implications for work on reminiscence and person-centred care. These elements are then drawn together in an exploration of the tensions presented by clothing in dementia care settings.

Dress as embodied social identity

Dress plays an important, though often unacknowledged, role in the reproduction of social order, forming one of the ways in which social difference is made concrete and visible (Breward, 2000; Entwistle, 2000). There is a long history in sociology of theorising the links between clothing and identity, especially the master identities of gender and class. The sociological analysis of dress indeed has its origins in work exploring the role of class; though recently more pluralistic, bottom-up accounts have questioned this dominance (Bourdieu, 1984; Crane, 2000; Davis, 1992; Simmel, 1904). Gender has similarly been

regarded as central, with many theorists presenting it as the crowning preoccupation of fashion (Davis, 1992; Tseëlon, 1995). It certainly forms one of the most clearly marked aspects of dress across most societies. It is closely implicated in the reproduction of gendered identities, acting to deliver gender as self-evident or natural, reproducing it as a form of body style (Butler, 1990, 1993). Such approaches have been extended to other master identities such as 'race', ethnicity, sexuality (Holliday, 2001; Rolley, 1993; Tarlo, 2010). Age, however, has been neglected in these analyses, reflecting the ageism of both sociology and wider society, though work on clothing and age has recently begun to emerge (Fairhurst, 1998; Holland, 2012; Twigg, 2007, 2013).

Most work on dementia, however, has tended to treat the subject in a somewhat unitary way with regard to social identity, reflecting the dominance of the bio-medical account, and the general tendency to assume that age erodes other forms of social difference. However pioneering work by Hulko (2004, 2009) has drawn attention to the significant ways in which the experience of dementia is filtered and understood through the lens of social identity. Kontos (2004) in particular has explored the intersections between social class and gender, showing the ways in which embodied selfhood in dementia continues to express class habitus through habitual manners and gestures, including ones in relation to dress, as her celebrated example of the pearl necklace shows. Ward and Holland (2011) in their study of hairdressing are similarly alert to the ways in which bodily appearance and presentation reflect social identity, although their focus is on the unexamined heteronormativity that dominates appearance management in care homes. Increasingly such analyses acknowledge the significance of intersectionality (Anthias, 2001; Hulko, 2004; Valentine, 2007), and the ways in which identities are fluid and complex, intersecting in variable and contingent ways.

The everyday practice of dress

This more complex account of identity fits well with the tradition in dress studies that, drawing on social anthropological influences, has emphasised the lived experience of dress, and the ways in which individuals construct their identities through everyday, embodied practices of selecting, managing, and wearing clothes, contextualising them within their lives, and specific interactional contexts (Guy, Green, & Banim, 2001; Weber & Mitchell, 2004). Here meaning is generated and negotiated at the level of the individual rather than in top down processes of ascription (Woodward, 2007). Entwistle, drawing on Goffman, describes how practices of dress are shaped by social and cultural norms concerning the ‘presentation of self’ in everyday interactions, as well as our ‘intimate experience’ of our bodies, so that dress needs to be understood as ‘situated bodily practice’ (Entwistle, 2000, p. 11). Dress thus plays a central part in the on-going, day-to-day negotiation of self.

Dementia, however, is often assumed to disrupt these processes, eroding the capacity of individuals to express themselves in this way. Neglect of appearance, particularly in those previously smartly presented, is often seen as an early sign of the condition (Jenkins & Price, 1996). Dementia disrupts the ‘habitual body’ (Phinney & Chesla, 2003) and with that the ability to perform everyday tasks. Problems over recognition, orientation, concentration and sequencing undermine the ability to dress in an intentional and expressive way (Bassett & Graham, 2007; Feyereisen, Gendron, & Seron, 1999; Heacock, Beck, Souder, & Mercer, 1997). Keady and Keady (2005) relate how memory problems can create challenges in adhering to social norms of dress, describing the embarrassment caused by failures of dress. These can be compounded by fears regarding societal judgements about competency and mental status indicated by appearance that fails to meet social norms (Entwistle, 2001; Hurd Clarke, 2011; Twigg, 2007).

Against this, however, we can put evidence that suggests individuals can retain engagement with dress at an embodied level. Qualitative studies that have explored ‘living with dementia’ suggest that clothing can be significant for the identities of individuals with the condition. Research on people with dementia who campaign for social change, for example, found that they often included photographs of themselves wearing suits and smart clothing in their photo-diaries, reflecting the significance of clothes for conveying a professional image (Bartlett, 2012). Bamford and Bruce (2000) reported how people with dementia valued bathing and hairdressing services that enabled them to feel ‘clean’ and ‘presentable’. Hubbard and colleagues (2003, p. 354) describe an example during observations in a care home, when a woman with dementia scratched off some food from her skirt, and then tried to hide the part of the garment that was dirty. When asked what she was doing she said ‘nothing in particular’, but her non-verbal behaviour indicated her continuing concern about this mark on her clothing. It is sometimes assumed that concern over appearance and dress fade with the advance of the condition, as capacity, for example, to recognise the self in the mirror is lost. Kontos’s (2004) ethnographic account, however, shows how clothing and appearance can remain important at a pre-reflective, embodied level even in the context of relatively advanced dementia.

Clothing and the materiality of dress

While dementia may disrupt the ability to dress independently, research suggests that the tactile, material aspects of clothing can remain important for people with dementia at an embodied, pre-reflexive level, as part of ‘the environment closest in’ (Twigg, 2010, p. 4). The immediacy of this can be significant because people with the condition may experience episodes of greater mental clarity in which they are able to recognise close surroundings in the form of clothes, and these can thus help provide a sense of temporal and spatial orientation. For instance, clothes usually worn for relaxation can be prompts to remind

someone that they are at home not work (Alzheimer's Society, 2011). Maintaining the sartorial distinction between day and night wear can act similarly.

As material objects, clothes are also significant in personal biography (Woodward, 2007), preserving, evoking and 'materializing' memories through their relationship with embodied practices (Hallam & Hockey, 2001). Clothes are particularly powerful 'memory objects' because they are not just owned by people, but worn by them; and the appearance, 'feel' and texture of garments can induce strong affective and emotional reactions (Ash, 1996). Like other 'biographical objects', clothes 'become entangled in the events of a person's life and used as a vehicle for selfhood' (Hoskins, 1998, p. 2). They can facilitate the construction and retelling of embodied biographical narratives (Hockey, 2012; Twigg, 2009; Weber & Mitchell, 2004), which are shaped, as we noted, by complex and shifting intersections between different aspects of identity (Woodward, 2007). Due to their interconnection with memories of particular people, events, and aspects of identity, people often 'hang on to' clothes long after they have stopped wearing them (Banim & Guy, 2001), or retain items of clothing which belonged to a deceased loved one (Ash, 1996; Hallam & Hockey, 2001).

Objects, images and sensory stimuli can be important for evoking memories for people with dementia; and have been used in reminiscence work as 'memory prompts', helping to overcome impairments in verbal communication and recall (Brooker & Duce, 2000; Bruce & Schweitzer, 2008; Gibson, 1994). Handling items of clothing and fabrics can bring back 'intense' memories of people, events, and emotions (Wallace, Wright, McCarthy, & Oliver 2011, p. 5). Fabrics such as satin, fur and velvet are 'particularly pleasurable to handle' and evoke 'the feel of the past' (Schweitzer, Bruce, & Gibson 2008, p. 62). Visual images of clothing captured in photographs and old film footage can also spark memories among people with dementia, for example, memories of wedding outfits (Schweitzer, 2007) 'knitted bathing costumes' and '1960's fashion mistakes' (British Broadcasting Corporation (BBC), 2012).

Re-enactment can help trigger memories, including re-enacting memories of ‘dressing up and going out’ (Schweitzer, 2007). Sometimes people with dementia are able to ‘show’ memories they cannot verbalise; for instance, when given a bar of soap, washboard and an old shirt, one woman was able to re-enact memories of wash day that she could not describe (Schweitzer, Bruce, & Gibson 2008, p. 30), illustrating the robustness of embodied, tacit knowledge, wherein we ‘know more than we can tell’ (Polanyi, 1966, p. 4). Clothes and sewing equipment are particularly useful in stimulating memories for women, reflecting earlier gendered and generational biographies.

Reminiscence work can help preserve identity and personhood, so that an understanding of life-history can be used to inform person-centred dementia care (Goldsmith, 2002; Kitwood, 1997; Williams & Keady, 2006). This can be extended to dress; and awareness of the clothing preferences of people with dementia has been described as a good indicator of person-centred care (Brooker, 2007). However, moving into residential care often results in the loss of personal possessions - including to some degree clothes - disrupting connections to memories, biographies, and identity (Fairhurst, 1999; Mountain & Bowie, 1992). Enabling people with dementia to retain their own clothes and objects is recognised as important in dementia care (Brooker, 2007), although the practical challenges of managing clothing within care settings can place limits on this.

Negotiating dress in the context of care

Maintaining individualised dress can be an important part of supporting identity in the context of care and can help create a benign interactional environment that supports embodied personhood. Reed-Danahey (2001) describes how care workers can take great pride in ensuring that residents are not recognisable as having dementia during care home outings, helping to prevent stigmatisation in social interactions, and preserving dignity and

embodied personhood. By contrast forms of dress coded as distinctive to dementia – loose babywear in pastel colours, garments that allow for easy dressing, the absence of supportive underwear, open backed dresses, neglected or standardised hair styles – act to undermine social identity and status, creating the classic appearance of the dementia patient.

As dementia progresses, however, the relation between embodied, everyday practices of dressing and identity can become disrupted, and family carers and / or careworkers are increasingly drawn into making decisions about clothing, ‘taking over’ tasks such as dressing, at times reinforcing dependence through ‘learned helplessness’ (Beck, Heacock, Mercer, Walton, & Shook, 1991; Cohen-Mansfield et al., 2006; Fossey, 2008; High & Rowles, 1995). Dress can become a site of struggle, as people with advanced dementia resist daily routines of dressing and undressing, or undress in inappropriate situations (Iltanen-Tähkävuori, Wikberg, & Topo, 2011). Maintaining privacy and dignity while conducting intimate bodywork such as dressing can be challenging for careworkers (Chatterji, 2006). Carework can at times be transgressive, ‘dirty’ work that is most easily accomplished at a psychic level by techniques of distancing and depersonalisation (Twigg, 2000). Maintaining personalised, ‘normal’ dress can help workers resist this dynamic of disengagement and othering.

Clothes can be particularly significant for relatives and family carers, maintaining continuity with the embodied biography of the person they love and knew (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008). Like other material objects, clothes can have special meaning as presents where, particularly in the context of the care home, they provide an important focus for gift giving and the expression of love. Their loss or careless mixing up can be a source of upset and anger. Relatives can also be distressed to encounter their family member dressed in a way that is discordant with their previous practices, with hair styles, make up, nail polish – whether the presence or the lack of it – that are foreign to them. Though relatives often try to

inform careworkers about clothing preferences, they are not always noted or acted upon by staff (High & Rowles, 1995).

Reminiscence and life-history approaches can be applied here to improve understandings of residents' past clothing preferences, and make practices of dressing and undressing more amenable to them (Kitwood, 1997). There are, however, tensions between maintaining previous forms of dress, particularly where formal in character, and the demands of comfort and the easy provision of care. For example, dressing men with dementia in jogging bottoms rather than fly-fronted trousers may be at odds with their embodied biographies and specific forms of masculine identity, but it may make delivering personal care easier. Similarly the absence of supportive underwear in women may contribute to the appearance of the dementia patient, though it may be more comfortable for the individual in the life they now live. There can be tensions here around imputed wishes, and *who* this work on appearance is for.

Bamford and Bruce (2000) found that family carers sometimes placed greater emphasis on appearance and hygiene than the person with dementia, and had trouble separating their desired outcomes of services from those of the person they care for. It is often argued that there is an overemphasis on managing bodies and appearance in care homes, typified in Lee-Treweek's (1994, 1997) account of the 'lounge standard resident' and that this is at the expense of the interactional and social aspects of care (Ward et al., 2008).

Conclusion

This article has explored the implications of clothing and dress for preserving identity and personhood among people with dementia, challenging common perceptions that clothing is irrelevant for people with the condition. This is in keeping with recent approaches to personhood in dementia care that have highlighted the embodied, pre-reflexive elements of selfhood. Drawing together literatures on clothing, dress, identity, and material culture, with

qualitative research on dementia, everyday life and care, it provides a framework for beginning to conceptualise these issues. These literatures illustrate the significance of embodied practices of dress for how we are perceived in everyday interactions and the way clothing acts back on our sense of self that has on-going relevance for people with dementia, and their carers, relatives and careworkers.

The arguments presented in this article also have implications for practice in dementia care. While practices in care settings have moved on considerably from the earlier days of institutional dress (see Twigg, 2010), clothing has received little attention in the literature and research on dementia care. As demonstrated through reminiscence work, the material, embodied relationship we have to clothing, which is embedded within our biographies and sense of who we are, means that - like other material objects - clothes can evoke forgotten personal histories and memories. The maintenance of familiar items of clothing can thus be important in the provision of person centred care, and to supporting embodied identity and personhood.

There remain tensions and challenges, however, between forms of dress that make the provision of care easier, and those that maintain dignity and selfhood. Furthermore, while studies illustrate how the clothing and appearance of people with dementia can be important to their carers and relatives, it is not always clear how far people with advanced dementia find extensive attention to their appearance beneficial. As demonstrated in studies which foreground the voices of people with dementia, the use of creative communication techniques may enable their perspectives on this issue to be better understood.

While suggesting the significance of clothing and dress for dementia care, this article also highlights a dearth of research in this area, and raises a number of issues and questions to be explored in future work. Such research would further expand the considerable body of

qualitative work on everyday accounts of living with dementia, and their connection to the experiences of carers, relatives and care workers. It would also extend the scope of sociological and interdisciplinary work on clothing and dress, which has begun to consider dress as an embodied practice, but has yet to explore everyday embodied practices of dress among people with dementia, or those with other cognitive or physical impairments. Important questions remain concerning how dementia affects everyday decision making around dress, and the relationship between dress and embodied identity. These issues will be explored as part of the Economic and Social Research Council (ESRC) funded Dress and Dementia project, which aims to understand the role of clothing in the everyday lives of people with dementia, their carers and careworkers.

Funding Acknowledgement

The article draws on the ESRC funded project Dementia and Dress, RES 062-23-3195.

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