



Place memory and dementia: Findings from participatory film-making in long-term social care



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ABSTRACT

A participatory film-making study carried out in long-term social care with 10 people with Alzheimer-type dementia found that places the participants had known early in life were spontaneously foregrounded. Participants' memories of such places were well-preserved, particularly when photo-elicitation techniques, using visual images as prompts, were employed. Consistent with previous work on the 'reminiscence bump' in dementia, the foregrounded memories belonged in all cases to the period of life between approximately 5 and 30 years. Frequently the remembered places were connected with major life events which continued to have a strong emotional component. The continuing significance of place in the context of long-term dementia care is considered from a psychogeographical perspective.

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1. Background

Traditionally, the medical model of dementia has tended to focus on the environment surrounding a person with dementia only in order to demonstrate his or her disorientation toward it. More recently there have been many projects to design therapeutic, or prosthetic, environments intended to compensate for such problems and a growth of interest in the strategies that people with dementia may use in order both to understand where they are within specific environments and to draw on concepts from the past in order to make sense of this information (see, for example, Orulv, 2010).

This paper draws on findings from a small-scale, mixed-methods participatory film-making study carried out between January 2013 and April 2014 to extend this debate. The participants were 10 people (eight women and two men) with an age range of 76–99 years (median 87) who had a diagnosis of Alzheimer-type dementia and were living in a long-term voluntary sector social care environment in the Northern UK. The overall aim of the study was to assess the impact of the film-making process on participants' well-being and social participation. Participants were therefore selected on the basis that at the outset of the study their levels of social engagement were a cause for concern.

At present there are many initiatives nationally and internationally to create 'dementia friendly communities', typically in

urban centres and public spaces (Keady et al., 2012). In reality, however, our participants had very little access to the external world, or even to the immediate environs of the care facility where they lived. Dementia-friendly principles have, however, begun to be translated to residential care environments by researchers such as Davis et al. (2009), reflecting a growing awareness of the importance of the environment and its hospitability, or indeed lack of hospitability, for people with dementia. A growing body of work has also started to focus on the ways in which people with dementia living in long-term care environments interact with spaces and places often not of their own choosing. Harnett (2013) notes, for example, how people with dementia 'carve out spaces' where they can obtain temporary respite from rule-governed and task-oriented institutional regimes, and identifies 'recollection talk' as one of two main tactics for framing such respite spaces.

The findings presented below add to this emerging body of data, by suggesting that much of this recollection talk relates to remembered geographical spaces that are meaningful to the person from his or her earlier life. Like McColgan (2005), we found that participants had developed agentic strategies for resisting present day constraints on their choices about how and where to live. We did not, however, find that their longing was always to return to what McColgan (2005: 411) describes as a 'safe maternal space'. As Varley (2008) has noted, feminist writers have been at pains to deconstruct the notion of the home as a depoliticised place of refuge and, as will be seen below our findings are more complex in this respect. Some participants' childhood homes had not been places of safety, and a number had previous experience

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of being displaced or ‘un-homed’ in some significant way which remained salient to their interpretations of being in a care environment in the present day.

2. Key themes

Findings on the formal measures used for the study (well-being, social participation and occupational diversity) were all positive (Ludwin and Capstick, 2015). The present paper is based, however, on a secondary analysis of the content of the films themselves, and here we aim to enhance understanding of the historical significance of place in emotional memory for people with dementia by exploring in depth some of the ‘patterned regularities’ (Wolcott, 1994) in participants’ choice of subject matter for their films. Through critical engagement with transcripts and fieldnotes three overarching themes emerged: freedom and escape, historical trauma, and overcoming adversity.

These themes lend support to recent work which has suggested the need for a change of focus in social research on dementia, from psychological needs to human rights (Bartlett and O’Connor, 2010; Gilmour and Brannelly, 2010). In relation to the theme of freedom and escape, it may, for example, be theorised that one of the ways people with dementia commonly resist the institutional regimes discussed by many previous writers from Gubrium (1975) onwards, is to make an imaginative retreat to a more hospitable or personally meaningful remembered environment. In other cases we found, that environmental or interactional features of the present day care environment appeared to trigger memories of location-specific traumatic earlier life experiences. Such experiences often intersected with social and national history in ways that have been somewhat overlooked in the literature; for example, two participants spoke frequently of experiences of being evacuated during WWII, suggesting that they drew parallels between this earlier life event and their current situation. Participants frequently drew on concepts such as neighbourliness, community values or personal determination to explain how they had met, and continue to meet, such challenges.

Emotionally charged autobiographical memories laid down early in life are known to be less compromised in dementia than are more recent memories, with consistent evidence of a ‘reminiscence bump’ between the ages of approximately 5 and 30 years (Gluck and Bluck, 2007; Thomsen and Berntsen, 2008). Chaudhury (2008) found that memory for familiar places remained strong for people with dementia. Recent work by Bonifas et al. (2014) among others, demonstrates that long-term care environments may often not be experienced by those who inhabit them as places that facilitate emotional or physical health and well-being, and although not explicitly related to people with dementia, Rose’s (2012) paper on therapeutic landscapes suggests that ‘landscapes of the mind’ – that is, imagined spaces and places – can be drawn on in order to cope with less pleasant experiences in the here and now.

The significance of metaphor in the stories told about themselves by people with dementia has been noted by Cheston (1996). Previous narrative biographical work carried out in care homes as part of the Trebus Project, a London-based series of arts projects involving people with dementia, of which the first author is a co-editor, also demonstrated a strong and consistent tendency for people with dementia to locate their stories in geographical space and place. Analysis of Bryce et al.’s text shows that, in response to the invitation, ‘Tell me about yourself,’ the majority of contributors mentioned a specific place early in their story. Leonard, for example, begins his narrative: “I was born directly – almost mathematically – opposite the Tube entrance in Hampstead...at the end of the street that runs straight down and curves to the right”

(Bryce et al. 2010: 47). The regularity with which the narrators make such references suggests that there is considerable potential for applying psychogeographical theory to dementia.

3. Psychogeography and dementia

Originally associated with the work of the Situationists, psychogeography has been described as the study of the “specific effects of the geographic environment, consciously organised or not, on the emotions and behaviour of individuals” (Debord, 1955). Later writers in this tradition have argued that such effects are as much, if not more, significant than names and dates in their connection with inner life. Bachelard (1994) tells us, for example that biography and autobiography are not merely a matter of narrative, but also involve what he terms ‘topoanalysis’, or investigation of the places we have inhabited. It has widely been assumed that psychogeographical practise necessarily involves walking, particularly in urban environments. Relatively less attention has been paid within psychogeographical studies to the application of psychological theory, including the impact of remembered places on emotional affect. As Coverley (2010: 68) reminds us, however, there is alternative tradition within psycho-geography which has always embraced the concept of mental travel as a means by which to ‘survive in hostile territory’. Capstick (2015) suggests that psychogeographical concepts such as the *dérive* (or intentional ‘wandering’) may also offer many new insights into the spatio-temporal disruptions characteristic of dementia.

Wiersma’s (2008) study involving veterans with dementia notes that her participants’ construction of a sense of place in the present was often ‘viewed through the lens of the past’ and that the values and ethics they had previously brought to bear continued to be significant to this enterprise (Wiersma, 2008: 791). Capstick and Clegg (2013) study of the war narratives of three men with dementia also notes that historical trauma can be reactivated with the onset of dementia due to a relaxation of cognitive control over emotional memory, and that this can lead to the emergence of counter-hegemonic versions of historical events. Rusby and Tasker (2009) found that wartime evacuation could have lifelong effects on mental health and well-being, with age at the time and quality of care being significant factors. Cook et al. (2003) note that many aspects of a care environment may act as reminders of traumatic experiences, including television news coverage, the sound of other people in distress, and loud noises. They note, for example, that ‘for women who have experienced captivity or violent assault, the presence of unfamiliar men or physical contact by male health professional may bring up unresolved trauma-related distress’ (Cook et al., 2003: 1223). As the findings discussed below demonstrate this seemed to be the case for at least one of the participants in our study.

4. Ethics

Ethics approval for this study was granted in September 2012 by the Social Care Research Ethics Committee for England (SC-REC) under Sections 30–33 of the *Mental Capacity Act (2005)* which applies in England and Wales. Seven of the 10 participants were assessed not to have capacity to consent for themselves to taking part in the study. They were therefore appointed either personal or nominated consultees able to give an opinion on their likely wishes and decisions. Ongoing process consent was negotiated at each new aspect of the intervention and took into account non-verbal as well as verbal indicators of withdrawal of consent, such as tiredness or anxiety (Dewing, 2007). Participants made editorial

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