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The carnival is not over: cultural resistance in dementia care environments

Abstract

Within the still-dominant medical discourse on dementia, disorders of language (such as dysphasia, aphasia, and perseveration) feature prominently among diagnostic criteria. In this view, changes in ability to produce coherent speech or understand the speech of others are considered to be a direct and inevitable result of neuropathology. Whilst an alternative psychosocial account of communicative challenges in dementia exists, emphasis here is placed largely on the need to compensate for deficits in the language or comprehension of the diagnosed individual and on his or her social positioning by 'healthy others'. Rather less emphasis has been placed to date people with dementia as social actors who create meaning and draw on contextual clues in order to give shape to their interactions. In this article we draw on Mikhail Bakhtin's concepts of the carnivalesque, heteroglossia, polyphony and dialogism to analyse a series of interactions involving people with dementia in day and residential care environments. Two main findings are foregrounded. The first, consistent with previous studies, is that many of the communicative challenges faced by people with dementia arise from the social environments in which they find themselves. The second is that the utterances of people with dementia in the face of these social challenges show many of the hallmarks of cultural resistance identified by Bakhtin.

Keywords: Dementia, communication, Bakhtin, carnivalesque, dialogism, cultural resistance.

Introduction

*To be means to communicate dialogically. When dialogue ends, everything ends.
Thus dialogue, by its very essence, cannot and must not come to an end.*

(Bakhtin, 1984: 252)

*Connie: We all stuck together...if someone was frightened you'd all gather round
and say 'Don't be frightened, it's over now.'*

Peggy: I don't remember; there's a lot I don't remember now.

Connie: I'll remember it for you.

(Conversation between two women with dementia: Bryce et al 2010: 76-77)

This article has grown out of our experience of conducting, since 2009, audio-visual research in three care environments for people with dementia in the Northern UK. The first and second projects were carried out in different voluntary sector day centres, one of which catered exclusively for people with early-onset dementia (aged 65 and under) whilst the second also provided for people over 65, with many of those attending aged over 80. The third study was undertaken in long-term, residential social care. The 10 participants in this final study ranged in age from 76 to 99 years of age, and many of them had relatively severe cognitive difficulties.

All three studies took an immersive approach which involved spending significant amounts of time in each care environment and getting to know the people who lived or spent their time there. One of the main outputs from the first study completed in 2010 and described in this article as CE1 (ie Care Environment 1), was a short film about the local city market, made with two women who had, at the outset of the study, a rather marginalised status within the day centre. The second project involved a number of people from Care Environment 2 (CE2) in the development of a short film to be used in practitioner education. In the final study, described below as CE3, the participants were supported in the co-production of individual short films about subjects of personal interest to them.

In this article we do not intend to describe these studies in detail, or to report on their overall findings. Instead we wish to discuss how spending time with people in such environments - sometimes as observers, and sometimes as partners in communication - has led us to a more nuanced understanding of the communicative challenges faced by people with dementia in group care settings, the strategies and resources they draw on in the face of these challenges, and how this requires us to revisit some of the orthodoxies about communication in dementia. Here, we will argue that new theoretical perspectives are needed, and we draw particularly on Mikhail Bakhtin's work on cultural resistance as a way of shedding light on this field of inquiry.

Background: the pragmatics of dementia

It is possible to identify three specific discourses in relation to language and communication in dementia, which might currently be described respectively as dominant, alternative and emergent. The dominant biomedical discourse attributes all actions and behaviour of the diagnosed person to the progression of neurological disease. The alternative psychosocial discourse recognises that communication with and by others in a social environment is also part of the picture. Finally, the emergent socio-political model recognises that much of the verbal and non-verbal communication of people with dementia is agentic, and is either a protest against their situation or a way of keeping self-esteem and a sense of personal efficacy alive in unpropitious circumstances. We will begin by introducing briefly the key characteristics of each of these models.

Biomedical discourse

Within the medical standard paradigm, problems with language are among the criteria required for a diagnosis of dementia (American Psychiatric Association, 2013). In biomedical texts the utterances of people with dementia are thus often reported as symptomatic of their condition. Naratnagam et al (2003) for example, draw attention to the tendency for people with dementia who vocalise in certain ways (for example, by screaming, shouting or muttering) to be labelled as 'noise-makers'. In this view, also, there is a typology of language disorders, including dysphasia (word finding problems), aphasia (absence of speech) or perseveration (repetitive speech) which are considered to be the result of

neuropathology in localised areas of the brain, in isolation from any compounding environmental factors. Language-based studies of dementia conducted within this paradigm have typically examined language that is elicited by standardized tests, or as a part of interviews or conversations with a researcher (Hamilton, 2008). Research on communication influenced by this paradigm generally focuses on the prevention or management of what are considered to be inappropriate forms of communication on the part of the person with dementia; for example, Cohen-Mansfield & Werner's (1997) study is concerned with the management of "verbally disruptive" behaviours in nursing home residents.

Psychosocial discourse

In opposition to the biomedical model, an alternative body of work grounded in humanistic psychology has been at pains to point out that the psychological needs of a person diagnosed with dementia remain unchanged, and that the responses and actions of others to that diagnosis can have significant impact on the individual's well-being and sense of identity (Kitwood, 1997). From this psychosocial perspective, since the environments in which people with dementia find themselves are often less than ideal, word-finding problems can also be regarded, at least in part, as the result of stress and frustration, absence of speech as the result of social disengagement, and repetitive speech as a result of one's attempts at communication being unresponded to by others.

Much of the research within this psychosocial domain has focused on understanding and improving institutional communication in dementia care settings. Different interactional contexts have been shown to result in differences in language produced and comprehended by people with dementia, and some studies have focused on identifying these contextual features (see: Light, 1993; Melvold et al, 1994). Ramanathan (1997) identified conversational partners, and the relationship between them as an influential factor on the language formulations used by individuals with dementia. Studies have also explored the experience of institutionalised forms of care for older people with dementia (see: Schreiner et al, 2005; Nolan et al, 1995; Bowie and Mountain, 1993; Gilloran et al, 1993; Hallbiorg et al, 1990; Norberg and Eriksson, 1990). These studies have mainly employed observational

and ethnographic approaches and have focused on aspects of daily living including levels of engagement, activity and communication.

What can be seen here, however, is that these formulations imply a largely passive role for the person with dementia as the 'spoken to', 'spoken for', or 'spoken about'; he or she is constructed as dependent, needy, and lacking in agency. Of concern here, for example, is the notion - central to all Kitwood's work - that the status of 'personhood' can be either bestowed or taken away from a person with dementia (Kitwood 1997). The categorisation by Sabat (2008) of those able to carry out such bestowing or withholding as 'healthy others', further compounds the unequal status ascribed to bestower and recipient. For all their attempts to alter the prevailing social milieu from a malign to a benign one, then, such formulations perpetuate a climate in which, as Langdon et al (2006) point out, people with dementia are rarely considered able to express their own views or contribute directly to social research.

Socio-political discourse

In our own findings from the three studies mentioned above what has impressed us more than the communicative difficulties faced by the participants is the persistence of their attempts to use every opportunity and means at their disposal to keep communication alive. The culture of care in the environments where our studies were carried out was relatively enlightened. Nevertheless we observed many instances of improvable communication on the part of professionals and direct care staff. What we also witnessed, however, was a range of coping, sense-making and self-determining strategies, which can perhaps be summed up informally as 'answering back'. Rather than the 'challenging behaviour' viewed, from a biomedical perspective, as a symptom of dementia, it has become increasingly clear over time that what we are observing is a form of cultural resistance. This is consistent with the emergence in recent years of a more socio-political model of dementia which Bartlett and O'Connor (2010) suggest has not been sufficiently theorised to date. Proctor (2001), for example, located her study on the power relationships between women with dementia and medical staff in the context of feminism as well as disability studies, but such examples are still relatively rare in the literature. More recently,

Behuniak (2010: 237) has pointed out that the politicization of dementia 'enables us to question the use of power, the extent of authority to be exerted over people with dementia, and the responsibilities of the community'.

Organisational culture and dementia care

In order to establish what it is our participants are resisting, we first need to say a little about organisational culture in dementia care. All communication by, with, and between people with dementia takes place in a social environment which has its own culture, consisting, as Davis and Nutley (2000: 115) point out, of assumptions ('taken for granted' views of the world); values (ways of judging right and wrong) and artefacts (eg dress codes, routines, recording practices). Kitwood (1995) outlined ten indicators of difference between what he termed 'old culture' and 'new culture' dementia care environments. The former is fundamentally a 'warehousing' model in which victims of an inexorable, progressive, incurable disease are merely kept clean and comfortable until they die. It is widely recognised, for example, that under-stimulation is a frequent characteristic of dementia care environments, with conditions of near-sensory deprivation not uncommon in long-term care (eg Harmer and Orrell 2008). Ronch et al (2013) discuss the relationship between language, power and organisational culture in the care of older people, and Åkerström (2002) for example, describes the way in which talk about "aggressive patients" was frequent and among workers in a care home.

The new culture envisaged by Kitwood is, by contrast, one of hope, enjoyment and meaningful activity, with the emphasis on living well in spite of dementia. Slightly later Kitwood (1997) presented the old/new culture distinction in terms of Type A and Type B organisations, with Type B organisations characterised by low levels of organisational defence, facilitative management style, and effective channels of communication. As Baldwin and Capstick (2007: 266) have pointed out this is an analysis based on ideal types, and does not confirm to the reality of any actually-existing care environment; 'any real world care setting will share indicators of both cultures rather than belonging to one or the other.'

Researchers working within the psychosocial tradition have rightly identified that the symptoms of dementia can be exacerbated by the deficient communicative strategies of others, and have conceptualised this in a number of ways, including 'malignant social psychology' (Kitwood 1997), 'malignant social positioning' (Sabat 2008) and 'narrative dispossession' (Baldwin 2006). Several studies have addressed the interactional dynamics between carers and residents and have shown a disparity between the socially-oriented interests of residents and the task-based agenda of the care staff (Small et al, 1998; Bender and Cheston, 1997; Iwaisiw and Olson, 1995). Similarly, the content of caring encounters and their relation to the wider conditions of care homes have been explored (Giles et al 1991; Lancy, 1985). Ward et al (2008) used video and ethnographic observation to capture the dynamics of interaction between people with dementia and caregivers, finding that episodes of communication were typically brief and task-oriented. Recent work by Kontos et al (2011) highlights the need also to understand interrelations between care home workers and their supervisors.

In this paper, we therefore begin to identify new theoretical perspectives on the communication of people with dementia in formal care environments which seem to us to do better justice to our findings than does the view from either biomedical science or humanistic psychology. 'In order to bring about real change in dementia care', this is to say, 'it may be necessary for this field to become more proactively oriented toward rights rather than needs and – as in the case of women's, black and gay rights before it – to learn that the personal is political' (Baldwin and Capstick, 2007: 273).

Critical theory and dementia care

A number of critical theorists have pointed to the resources developed by human beings under conditions of adversity. Often these are considered to lie on the theoretical fault line between agency and structure. Whilst postmodern theorists have generally been pessimistic about the power of individual agency to overthrow state structures, they have had less to say about the value of protest for maintaining hope and self-esteem under adverse conditions. There is, however, an earlier and still ongoing line of argument derived

from certain branches of poststructuralism, German critical psychology, and Russian cultural theory which offers a more optimistic view of human agency.

The German critical theorist Walter Benjamin notes, for example, that the real spoils of the struggle between the oppressors and the oppressed are not the material gains accumulated by the victors, but the 'courage, fortitude, humour and cunning' which the dispossessed gain in the process (Benjamin, 1970: 246). Žižek (1989) re-works Althusser's structuralist concept of interpellation in which human subjects are entirely dominated by hegemonic discourse. From Althusser's structuralist view there was no distinction between the *object* called into being by ideology and the *subject* who obediently arrives to fill the ascribed place: the possibility of human agency was completely quashed by the dominant state structures and ruling hierarchies (Althusser 1971). Althusser's theory would fit our purposes here, that is to say, if the object called into being by the hegemonic biomedical or psychosocial discourses of dementia (a generic diagnosed individual) was identical with any actual person who appears in a dementia care environment. In order to fulfil these criteria we can see that the person with dementia would need to be one who accepts unquestioningly the accuracy of his or her diagnosis and prognosis, and also accepts what this diagnosis implies about his or her social positioning by others. The fact that the participants in our study do not allow themselves to be mastered in this way gives support to Žižek's counter-argument (drawing on the earlier work of Lacan) that the human subject will always have an 'excess' over and above the role ascribed by ideology, and that this excess is evidenced in the form of protest, no matter how inchoate or attenuated, against the prevailing order. This concept of 'excess' is more robustly and engagingly developed, however, in the work of Mikhail Bakhtin, and it is to Bakhtinian theory that we now want to turn in order to develop our argument further.

Why Bakhtin?

Since Bakhtin was a literary theorist working predominantly in the first half of the 20th century, it may seem on the face of things a far stretch to apply his work in the context of early 21st century dementia care. We have not, however, chosen to draw on Bakhtinian concepts at random, but because they have a good, mind-to-world fit with our observations of, and interactions with, people who have dementia. In the following sections we explain

how certain concepts of Bakhtin's - the carnivalesque, polyphony, heteroglossia and dialogism - have fostered a different way of seeing action and interaction within the dementia care environments where our studies were carried out. For example, the polyphony or 'play of many voices' admired by Bakhtin in the work of Rabelais and Dostoevsky is a celebration of difference, of heterogeneity. What is radical about Bakhtin's thinking is precisely that it is drawn from real-world contexts and the day-to-day language of people who do not themselves produce literary texts, although they may be represented in them. So the methodological field which is a dementia care environment, as we view it through the lens of Bakhtin's theory, is a place of extreme differences, competing voices, and multiple speaking positions. People with dementia, just like the unruly 'folk' attending Rabelais' feasts and fairs, cannot conveniently be bidden to the place set out for them by the official order. The various speakers who arrive here are not the ones imagined by either biomedical or psychosocial orthodoxy; they are prone to turning the world upside down.

The carnivalesque

Bakhtin uses the term carnivalesque to describe popular humour, particularly when this is directed against officialdom. Historically carnival was an expression of mockery against church and state, and folk humour of this kind is, in Bakhtin's view, a form of cultural resistance. *Rabelais and his world* (RHW), the text in which Bakhtin (1981) advances his theory of the carnivalesque, demonstrates via the work of Rabelais (1494-1553) how carnival imagery was deeply embedded, and embodied, in the folk culture of the middle ages. This imagery is a form of robust, humorous, and often ribald resistance to the attempts of church and state to organise society in their own image. Bakhtin's text is structured around five key themes, which are the subject of individual chapters: laughter; the marketplace and its language; popular-festive forms and images; banquet imagery, and the grotesque image of the body, particularly what Bakhtin terms its 'lower stratum'. Bakhtin suggests that Rabelais 'so fully and clearly revealed the peculiar and difficult language of the laughing people, that his work sheds light on the folk culture of humour belonging to other ages' (RHW: 484). Carnival laughter 'builds its own world in opposition to the official world' and has 'an essential relation to freedom' (RHW: 88-89).

Accordingly, we have found that the stories told to us by people with dementia, and their spontaneous speech with each other, often rich in vernacular detail, are neither dominated by official history nor compliant with it. Humour – sometimes scatological – is a frequent feature. Much of this humour is easily dismissed, however, from the point of view of hegemonic discourse related to people with dementia as, for example, ‘verbal abusiveness’, or ‘sexual disinhibition’. Here it is the context which determines what is considered appropriate, so that an off-colour joke which would not be out of place in a barroom or on a factory floor is classed as a symptom of dementia or form of challenging behaviour in the lounge of a voluntary sector care home. Much of the humour we observe is also linked to a philosophy of laughing in the face of adversity. One woman who grew up in extreme poverty in the 1930s, for example, talks of herself as coming from ‘(Place name) - where they eat muck, but wash it first’.

The marketplace and its language

In CE1, as we have already mentioned, a short film about the local market was one of the main outputs. Footage recorded in the local market – a large, canopied, Victorian landmark building – was edited together with a soundtrack composed of the comments of two women in response to the images of various stalls. Although initially subdued, we found that the two women became increasingly animated as the film sequence went on; they seemed to regain a sense of ownership of the market and its contents, and to co-construct a dialogue related to their own roles as discerning shoppers (for a full discussion see Capstick 2011). Near the end of the film, for example, the two women comment, in relation to images of jars on a sweet stall:

P: We’ll have *all* the top row....

C: ..and we’ll have *all* the bottom row; (to researcher) we’ll give you one if you like!

An aspect of the film footage which no doubt made the market more real to the two women involved is the sound of various stall-holders shouting their wares in the background (‘He’s got lamb chops for sale’, as one of them comments). This is very reminiscent of Bakhtin’s discussion of the cries of the market place in Rabelais; these cries

were an essential part of the marketplace and street, they merged with the general popular-festive and utopian world. Rabelais heard in them the tones of a banquet for all the people, “for all the world”. These utopian tones were immersed in the depths of concrete, practical life, a life that could be touched, that was filled with aroma and sound (Bakhtin 1984: 185).

We have found that participants in all three studies refer frequently to the buying and exchange of goods, shops and shopping, the challenges of finding and cooking food, and different kinds of traders and vendors of goods. One woman in CE3 often repeats a playground rhyme referring to ‘tingalaries’. This word was not familiar to us, but we found that ‘tingalary men’ was a term of Irish origin used by the largely migrant population in the area where she grew up to refer to, predominantly Italian, street hawkers, barrel organ players and ice-cream vendors. Since the term was still commonplace in this woman’s childhood we can trace a line of descent here from the ‘peculiar culture of the marketplace’ in the 16th century with its ‘itinerant hawkers, gypsies, and ...popular argot’ (RHW, 155) through to the street language (or ‘billingsgate’ as Bakhtin describes it) of the Northern UK in the 1930s.

Not having money to pay for things, or not having control over one’s own money, is a frequent source of anxiety among people with dementia in formal care environments, particularly at mealtimes. After a morning spent talking about her life story in the garden at CE3, for example, one woman said ‘Thank you, I enjoyed that, and when I get some more money we’ll have a *good* do.’ This is simultaneously a rueful acknowledgement of not being able to return hospitality at the present moment, and an invitation to future gaiety. Another woman, visited in her own apartment in CE3, was worried that she didn’t have ‘anything in’ to offer us to eat. On more than one occasion she presented a plate of dry breakfast cereal rather than offer nothing to her guests.

Popular festive forms

‘Popular-festive forms’, as described by Bakhtin, are ‘deeply traditional and popular, bringing an atmosphere of freedom, frankness and familiarity’ (RHW p 195). Within these popular-festive forms, singing is considered by Bakhtin to be a form of ‘profane love’. In

CE3, in particular, self-initiated community singing is frequent, and the songs popular with participants tend to lie within the tradition of pub and piano sing-alongs, music hall and variety. Often these songs have humorously subversive themes such as the 'moonlight flit' (leaving rented accommodation without paying off arrears) in 'My old man said follow the van'; the adulterous or bigamous relationship suggested by 'My wife won't let me'; and the veiled sexual allusions of 'Daddy wouldn't buy me a bow-wow'. Also popular were the more conventionally romantic love songs of the 1940s and 50s. One woman had lived with her widowed mother and siblings in a public house owned by another family member for several years as a child. She knew a vast range of popular songs by heart and would often sing aloud, apparently as a way of preserving her own identity and personal relationships. One song of which she was particularly fond (*I don't care who knows it, I'm in love with you*), was always introduced with the words 'And my husband used to sing to me....'

Dance halls, cinemas, high days and holidays (the local 'feast', fair, sports day or races) were also frequent subjects in spontaneous reminiscence belonging to Bakhtin's domain of the popular festive form.

Banquet imagery

As already mentioned in the discussion of marketplace imagery above, discussions related to food, its sufficiency or inadequacy, the problems of cooking and 'having enough to go round' are frequent subjects of discussion. One fieldnote from CE3, for example, describes the following interaction between Residents 1 and 2:

Res 1: [singing] 'You're the cream in my coffee....' [Res 1 can't get beyond this first line, which she repeats several times.]

Res 2: [emphatically, after a few repetitions] 'You're the SALT IN MY STEW!'

Res 2 [a few minutes later] 'Stew and dumplings! Rice pudding! You never had any money, but you always got a proper dinner!'

'Not going hungry' in the face of poverty and wartime rationing was a repeated theme of several of the female participants in CE3 and was always associated with their mothers' or grandmothers' resourcefulness in baking their own bread, cakes and puddings, and being able to make meals out of anything. A woman who originates from Liverpool, which historically has had a large Irish-Catholic population, told us what seemed at first to be the unlikely story of a shop that sold nothing but potatoes (or 'spuds' as she describes them) but this turned out to be quite true. One woman spoke in detail about her father buying eggs and other produce (presumably on the black market) from a work colleague who lived in the country, and how her mother's face 'lit up' when he brought them home. Another, who sadly did not live to see the end of the study, gave us the recipe for making a rabbit pie, right down to detailed instructions for skinning the rabbit.

The bodily lower stratum

Discussions of marital relationships, childbirth and sex are more frequent than might be expected on the basis of published research, which has traditionally indicated increasing sexual apathy among this population (eg Miller 1995). As Ward et al (2005) have more recently pointed out, however, the almost constant surveillance in most long term care facilities makes any overt sexual expression almost impossible. One woman in CE3 who worked in a maternity hospital was particularly interested in talking about how patients and their husbands often asked her for advice about intimate problems which she was able to help with. This same participant has an interesting double-take on the seamier aspects of life, often telling us how her father did not allow bad language, and then regaling us with schoolyard jokes such as 'Have you got 'em; spots on yer bottom'. Another woman explains that she had a job 'sewing mens' trouser flies', which is met with the laughing question from another 'Were the men in them at the time?' In one audio recording three women are singing, and laughing uproariously at, a playground song about three old ladies locked in a lavatory. Sung to the tune of the traditional song 'Johnny's so long at the fair' this incorporates elements of both the bodily lower stratum, and marketplace imagery.

The following sections present a more detailed analysis of some of the material from these transcribed audio-recordings which we believe conform to Bakhtin's concepts of polyphony, dialogism and heteroglossia.

Polyphony: The play of many voices

Polyphony is a term Bakhtin (1981) used to advance his belief that truth requires many voices and can neither be held within a single mind, nor spoken by a single mouth.

According to Rudrum (2005: 34) Bakhtin views dialogue as 'a site where no single discourse absolutely triumphs over the rest'. In this view each individual's voice is understood to shape the character of the others' speech; our utterances are shaped by those with whom – or for whom – we speak. Value is attached to keeping many voices in play rather than a single truth. In the context of dementia, the concept of polyphony helps to remind us that people with dementia are not homogenised by their diagnosis but speak in many, and diverse, voices. The following extract, which comes from an interaction recorded in CE3 involves three female residents who are all in their late 80s and have relatively severe cognitive difficulties. Researcher 2 (Res 2) is filming Researcher 1 (Res 1) showing pictures to Nora (Nor) in the communal lounge as part of a data collection exercise. Some of the pictures have written captions. Olive (Olv) is sitting alongside Nora, and Lily (Lil) is sitting across the room with a small group of other residents:

Extract 1

1. Nor: . . . the Jarrow crusade. I mean now I can
2. hardly remember[it
3. Olv: [A crusade
4. (0.5)
5. Nor: Hm::
6. Res1: It was be[cause
7. Nor: [And I mean they would (.) all,
8. all be very [poor
9. Elsie: [One two three [h::
10. Nor: [Well I mean,
11. we were all poor h-h:-h-hu :hh
12. Res1: It was because [of
13. Lil. [Nora!

14. Res1: unem[ployment
15. Lil: [Nora!
16. Res1. N[one of th – they didn't have jobs=
17. Lil: [Nora!
18. Res1. =did they.
19. Nor: No
20. Olv: °No°
21. Nor: No
22. Lil: Nora! (0.5) Where are we?
23. (2.7)
24. Nor: ((To Res1)) Would you do me a
25. big favour ::hh
26. Res1: h-hm
27. Nor: Just tell my moth[er where we are
28. Olv: [I saw em on the tele
29. Res1. Yea, I was going to- [erm:
30. Nor: [She'll never rest
31. (8.0) ((Res1 crosses the room to speak to Lily))
32. Res1: ((To Lily)) This is a map of Leeds.
33. Olv: This is it on the table?
34. Nor: Yea, yes.
35. Lil: What's it a map of?
36. Res1: It's a map of Leeds
37. (1.5)
38. Lil: W'll (.) aren't-aren't we staying here?
39. (1.5)
40. Res1: Yea.
41. Lil: Well (.) where are we going?
42. Olv: k-h[::eer
43. Nor: He-[h-he-heh=
44. Res1: [I don't know
45. Nor: =k-heh-he-heh: [he-he-heh

46. Lil: [How long are we going
47. to be here?
48. Res1: We're going to be here until lunch time.
49. Nor: K- heh-he -heh :hhh oh dear.
50. Olv: And then we're havin some lunch.
51. Res1: Yea
52. Lil: Where are we havin it?
53. Res1: Just down the corri[dor
54. Lil: [What time?
55. (0.8)
56. Res1: Er:: at half past twelve
57. Lil: And what time is it now?
58. (2.0)
59. Res2: It's quarter to [twelve.
60. Res1: [quarter to twelve
61. Nor: ((To Olive)) Does she know that though?
62. Res1: When we've finished looking at these pictures
63. we can have[a game of dominoes
64. Nor: [Oh look (.) the Jarrow crusade
65. (2.0)
66. Olv: [((to Norah)) where's the - how's that then?
67. Lil: [((to Res1)) Who's playin dominoes?
68. Nor: [((reading picture caption to Olive)) But I had a lovely mother, a dear
69. [little [^{*} mother ((^{*} multiple overlap with line 69))
70. Lil: [((angry, unclear))
71. Res1: [((to Lily)) It's alright.
69. Olv: [((reading another picture caption)) ^{*} But the money was tight
70. (1.0)
71. Olv: I said they was there, cos the money
72. was tight.
73. Res1: [((in background, to Lily)) it won't be long
73. Nor: [Ohh, I'm not trying to prove that

74. they were. .
75. (1.0)
76. ((Res1 returns to Nora and Olive))
76. Nor: ((to Res1)) °She's a bit clever y'know°

In this sequence interaction takes place on multiple levels, as the utterances of the four participants intertwine, and at times compete. During our fieldwork in CE3 it had already become clear that Nora and Lily had a complex relationship with one another. Staff members told us that they had previously been close friends, and that Nora had often been called upon to placate Lily when she was upset about something. Over time, Nora had become less able to deal with these requests, and, whilst usually still warm towards Lily, she was now clearly trying to extricate herself from the emotional demands of the relationship. Nora frequently referred to Lily as 'my mother', so possibly aspects of this relationship were also reminiscent of that with her own mother. On previous occasions when we worked with Nora we had noticed that Lily was prone to trying to draw Nora's attention away from her interaction with us. On this occasion, a further dimension was added by the fact that Olive was also competing to be noticed by Nora, and possibly by the two researchers. However, Olive's part in the interaction is noticeably more restrained and conventional in terms of turn-taking than Lily's. Olive is also content to let Nora set both the pace the agenda, and does not place any emotional demands on her.

What happens, then, is a prolonged and determined, but ultimately unsuccessful, attempt by Lily to become part of the group, and an interaction between Nora and Olive which, we might suspect, is more successful as a result. Interestingly, in this respect, every utterance of Lily's until line 67 is couched in the first person plural 'we', whilst Nora several times refers to Lily as 'she', thereby rejecting Lily's claim to group membership. In-group/out-group interactions of this nature are rather frequent in our experience, but are often overlooked by staff members who spend little time in direct interaction or observation of communal areas. The fact that residents themselves, rather than staff, are left to deal with each other's distress can then lead to the ostracism of people with dementia like Lily, who require a lot of reassurance.

Interaction between Res1, Nora and Olive proceeds without problems until line 12. Nora is the intended focus of the researchers' attention, the pictures that Res1 is showing her having been chosen in the light of several previous interventions. Olive attempts to join in with the discussion, but is not directly engaged by Nora. On lines 1 and 2, for example, Nora is responding to an image from 1936 of the Jarrow hunger marchers. Nora grew up in the North-East of England and has strong associations with this picture. Olive echoes Nora with her overlapping, '...a crusade'. On lines 7 and 8, Nora is developing a narrative about the poverty of the marchers, which Olive again overlaps (line 9). When Nora does not respond, Olive starts to count the men in the picture, 'One, two, three', but this turn is essentially autonomous.

When we reach line 12 the interaction between Res1, Nora and Olive is disrupted by Lily, who shouts to Nora from across the room. She does this three times (lines 13, 15 and 17) and is initially ignored until line 21-22, where a natural pause in the interaction gives Lily the opportunity to interject with a complete questioning turn, 'Nora (0.5) Where are we?' Nora does not respond directly to Lily, but after 2.7 seconds (line 23), asks Res1 to do so, referring to Lily as 'my mother'. Res1 then crosses the room, taking with her a map of Leeds with which she attempts to answer Lily's question about where we are, a tactic which has sometimes worked in the past. During the interaction between Res1 and Lily, Nora laughs nervously several times (he-he-heh) on lines 43, 45 and 49. Her statement 'She'll never rest', suggests not only concern for Lily but also recognition that there is a cause and effect relationship between failure to respond and her escalating levels of anxiety.

Nora is skilful in delegating Res1 to respond to Lily, using the quite sophisticated negotiating skill of requesting a favour, which it is not possible in this context for Res1 to refuse. Once Lily has the attention of the group, it is significant that she does not continue to shout, but follows the normal conventions of conversational engagement; on line 35, for example, she offers a direct question to Res1 about the map of Leeds. There is then a sequence between lines 46 and 61 during which all four participants are temporarily engaged in the same conversation, beginning with Lily's, 'How long are we going to be here?' a question which is clearly also of interest to Olive, who joins in at line 50, also using the inclusive 'we'. However, Nora's next turn again refers to Lily as 'she', thus breaking the potential for three-

way interaction. Nora and Olive then return to their original subject, reading aloud to each other from the photo captions, and engaging in a more reciprocal discussion than appeared to be the case at the outset. The complex sequence from line 64 onwards fragments into two simultaneous interactions (one between Lily and Res1, the other involving Nora and Olive). Nora's final remark to the returning researcher, 'She's a bit clever y'know' (line 76) is said quietly, and in an almost conspiratorial way, suggesting that Nora is well aware of the interactional ploys used by Lily and on some level admires them.

In the next section we will look in more detail at how these dynamics play out in the context of a day centre interaction where multiple voices, including those of care staff, may be in overt competition - not only with each other, but with a myriad other subliminal influences which permeate such environments.

Dialogism: the struggle to be heard

Bakhtin (1981: 273) stresses that dialogism, or 'double-voicedness', is 'a struggle among socio-linguistic points of view, not an intra-language struggle between individual wills or logical contradictions'. Vice (1997: 45) suggests that three key characteristics of dialogism are 'the mixing of intentions of speaker and listener...the creation of meaning out of past utterance, and the constant need for utterances to position themselves in relation to one another'. The next two extracts are taken from an interaction in CE2 initiated by Don, an 89 year-old man with dementia who was recovering from a recent hip operation. Here we suggest the simultaneously-recorded dialogue of the care staff exemplifies several of the elements identified by Vice.

Like many people with dementia Don's long term recall is good and he often recounts his experience of joining the RAF at the age of 17, and working on fuel supply in a variety of war zones (including Egypt) throughout the duration of the Second World War. Our impression is that this story is often repeated as a form of cultural resistance. That is to say, Don does not believe himself to fit the space ascribed to the '89-year old man with dementia' called into being by ideology, and he rejects this status by reiterating his exploits as a young man; an example of the 'excess' referred to by Žižek (1989).

The following sections focus on transcript extracts from the film record of this session. On the occasion when this particular sequence of interactions took place, the day centre lounge was particularly noisy, making a clear sound recording of Don extremely difficult. Multiple interactions were taking place between staff and residents in the room, and perhaps more significantly, among a group of staff in the adjoining kitchen area. In addition to Don himself, the participants in the extracts were three carers (CA1, CA2 and CA3) and two researchers (Res 1 – AC and Res 2 - JC). Researcher 2 is simultaneously filming the session.

In the extracts below Don was filmed talking to Researcher 1 in one corner of the lounge area. Across the room – some 7-10 metres away – the three care workers in the kitchen area were carrying on a loud and animated discussion. It is unlikely that the care staff group were in a position actually to hear what Don and the researchers were saying to each other. They will, however, have been aware that he liked to talk about his wartime experiences, and can probably anticipate what he is talking about on film. Don may also have been aware of some of the louder talk from the staff group – borne out by the fact that some elements of his narrative were completely obscured by it in the original recording.

Extract 2

1. Don: I don't know. I got demobbed from Germany. I got invited up to the wing
2. Commander's office quarters [and he said to me would I like to sign on?
3. CA2: [Is it permanent? Or is it agency this time?
4. Don: He said if you sign on you'll be a sergeant tomorrow . . . I said that's what you
5. think, sir. I want to go home to my family. I've done my whack.
6. CA3: Cos one night I'll work, I'll be off Monday. . .
7. CA1: Would you travel anywhere? If I says to you, do you wanna come and stay
- with me, you'd do it?
8. Don: I lost a lot of [mates
9. CA1: [If I said I were gonna take you to ...Egypt?

Here we can see a form of dialogism which might be described as ‘thematic resonance’. Don’s own monologue, i.e. the monologue that we were originally interested in capturing, makes sense in terms of its structure and sequencing, coming as a discrete and relatively self-contained element in a much longer war narrative. In lines 1, 2 and 4, Don describes arriving back from Germany, being summoned by his commanding officer, offered a commission, and his immediate rejection of this. What we hear of the carer interaction is thematically similar. We pick it up midway through a discussion about working hours and the difficulties of travelling to work (from line 3: ‘Is it permanent?’). However, what is interesting here is the tangential connections which are generated as the separate interactions play out. First, Don is talking about the offer of a job and his reluctance to take it because it would mean remaining a long way from his family: ‘. . . I said that’s what you think, sir. I want to go back to my family. I’ve done my whack. (lines 4 and 5). Here, Don cites a distinct example of his ability to challenge the voice of authority.

The carer interaction too, as it weaves its way around Don’s narrative, is focused on offers of work and travel to work (i.e. as a reason to find the offer wanting). At line 7, for example, we have carer 1 enquiring ‘Would you travel anywhere?’, and later, in line 9: ‘If I said I were gonna take you to. . . Egypt?’ This lighthearted presentation of hypothetical rewards by carer 1 has a further resonance with the commanding officer’s strategy to persuade Don to stay in the Air Force: ‘If you sign on, you’ll be a sergeant tomorrow’.

Another, more striking, example of the ‘mixing of intentions of speaker and listener’ can be found in Extract 3:

Extract 3

- 1 Don: I was there when the V bombs were coming over us. And the kites were chasing them.
- 2 Before they got to London, they shot them down.
- 3 Res2: ...Didn’t they flip them over with their wings?
- 4 Don: Sometimes, yea, they could do but I wasn’t there then. I don’t remember that.

- 5 CA1: Oh sorr[y]
- 6 CA2: [Soldier!
- 7 Don: I was never still.
- 8 CA1: Bang!-bang!-bang!-bang! –bang!!
- 9 Don: See I was in transport and I was all over...
 ((Here there is about two minutes relatively unbroken narrative in which Tom talks about his experience of driving a field ambulance from Hamburg to Arnhem))
10. . . . and Montgomery came back. I was with Montgomery in the
11. Middle East. Spitfires [and. . .
12. CA1: [Ahh, that's what that was.
- 13 CA2: When you carry a gun, you are fighting a [war.
- 14 Don: [It all seems like a dream
- 15 to me now; you know what I mean?

Carer 2 makes explicit reference to a 'soldier!' (line 6), while Carer 1 imitates gunfire (line 8). The fact that this is loud enough to be audible on the film footage means that Don will have been aware that he was competing with the interchange on the other side of the room. In this context his reference to 'never being still' coming as it does between these two militaristic utterances implies some resistance to his current situation. Possibly it implies 'I was never still *like I am now*' with reference not only to his immobility due to recent surgery but also the fact that he is confined to a corner of the room while the care staff's dialogue appears to exclude and dismiss him. Carer 2 then delivers the line 'When you carry a gun, you are fighting a war' (line 13), which is synchronous with Don declaring that 'It all seems like a dream to me now. . .'

The juxtaposition of military metaphors between the simultaneous interactions here is particularly fascinating. Whilst we do not wish to impose any kind of interpretative closure on this material, it adds to our growing awareness of the complex and multifaceted nature of communication in dementia care environments. Whether or not the carers borrow, consciously or unconsciously, from what they already know of Don's story, the mere fact

that such metaphors are chosen at all implies the use of cultural resistance on their part as well as Don's.

Heteroglossia: subverting the other's word

The findings presented in this section are taken from CE 3 and demonstrate how, as with Bakhtin's concept of heteroglossia, the dominant or 'prestige' organisational language of the care environment tries to extend its control, while the subordinated language of the residents tries, in White's words (1994: 137) 'to avoid, negotiate, or subvert that control.' Here, Olive, who also featured in Extract 1, draws on the presence of others, not themselves directly involved in the interchange between herself and a staff member, to co-construct a form of dialogue which is favourable to her own interests. This enables her to resist, at least momentarily, the prevailing regime of the care environment; one in which even the most basic physical functions are monitored and controlled by others. 'The word does not', as Bakhtin puts it, 'exist in a neutral and impersonal language... but rather it exists in other people's mouths, in other people's contexts, serving other people's intentions; it is from there that one must take the word, and make it one's own (1981: p.294).

As the recording begins, Olive is sitting in the main lounge area with a group of other residents. Two researchers are chatting informally with members of the group. There are various other activities going on around the room. The general atmosphere is lively and the audio-recording from which this extract is taken has a background of jumbled noise including fragments of speech, singing and TV noise. We join the interaction as a care worker approaches to speak to Olive:

(Res = researcher; Len = other resident; Cw = Care worker; Olv = Olive.)

Extract 4

- 1 ((Care worker approaches group))
- 2 Res: It's your[turn to go now Olive.
- 3 Len: [It should be.
- 4 Cw: Olive:: it's your turn no:w (2.0) going to take you

5 to the toilet and just check [your pad

6 Olv: [Wh::- whu-hh: I just

7 had- I had [one =

8 Cw: [Just for five minutes::

9 Olv: Just for five minutes?

10 Cw: Yes.

11 (1.0)

12 Olv: ((unclear)) I've got somebody with me.

13 Cw: Yea. [I'll take you to the- I'll take you to the toilet] .

14 [((loud voices / singing nearby - - - - -)]

14 (1.5)

15 Olv: To the where?

16 CW: To the toilet

17 Olv: Parlour?

18 Res: To- the-toilet

19 (2.5)

19 Olv: I don't want to go to the toilet.

20 (1.5)

21 Cw: I'll just check your pa:d

22 (2.0)

23 Olv: No: I know when I want to go to the toilet.

24 Cw: Yea.

25 (1.0)

26: Olv: And I always go (3.0) I've gone this

27: morni[ng

28: Cw: [Oli::: ve, sometimes it needs check:ing (1.0)

29 it needs checking y'know (1.0) sometimes it's

30 soaking wet (.) cos it needs changing (1.0) needs

31 changing (1.5) yea.

32 (2.0)

33 Olv: I really don't want to go.

34 Cw: You don't want to go

35 Olv: No.
36 (6.0)
37 Olv: ((To the researcher)) Do you want to go?
38 Res: I'm all right

From the perspective of the biomedical model of dementia what is happening here might be described as 'non-compliance with personal care' and viewed as a behavioural or psychological symptom of dementia (BPSD). Interpreted from the psychosocial perspective it would be viewed as multiple personal detractions (Kitwood 1997: 46) committed by the carer against Olive; for example, 'imposition' ('going to take you to the toilet and just check your pad'), 'stigmatisation' (referring to her need for continence aids in front of others) and 'invalidation' ('it needs checking/changing'). However, this fails to take account of the fact that the careworker is not responsible for the cultural regime of scheduled toileting (an *artefact* in Davis and Nutley's terms), but is put in the uncomfortable position of being required to implement it as a condition of employment. The cajoling tone that the careworker adopts here is evidence of a reluctance to persist with the 'organisationally-scripted' interchange. In keeping with its generally apolitical stance, then, the psychosocial model is keener to point to the 'uncaring' and 'unhomely' nature of care homes (eg Vladeck 2003), than it is to recognise that they are also workplaces where the rights to self-determination of workers are frequently overlooked and traduced.

In this extract, we would suggest that there is also evidence of several aspects of cultural resistance on Olive's part; for example, the expression of autonomy, an appeal for solidarity from the researcher, and persistence in the face of opposition. This is therefore an example of someone with dementia adopting an interactional strategy that takes advantage of the tension that arises when underlying interactional positions - which are routinely left beneath the surface - are brought to the fore. Residential care homes such as the one where our encounters took place have generally developed a set of informal norms whereby every effort is made by staff, visitors, and any other non-resident who engages with the arena, to maintain the impression of a normal, familiar, social environment. That is, one where people are free to do and act as they like within accepted social norms, and where overt

reference to the underlying restrictions and institutional routines which are a necessity of this kind of residential setting are generally avoided.

Whilst we need to be reflexive about the difference that factors such as our own presence might be making, over time our becoming familiar to staff led to a relaxation of any changes to their normal practice that might have been adopted for our benefit. We frequently noted, for example, that care staff came in already wearing rubber gloves and carrying packs incontinence pads with them – something that falls well outside normal social behaviour. It may also be that Olive herself was resisting a culture in which people can be subjected to this form of social embarrassment in front of visitors, rather than the suggested toilet visit itself.

From the start of the extract it can be seen that there is a tension between the ‘normal’ social engagement that Olive and the other residents are engaged in, and the intrusion of the care worker. The way in which this care worker undertakes the task (i.e. to take Olive to the toilet whether she needs to go or not), not only undermines the construction of the arena as a neutral social space, but overtly foregrounds its impersonal and institutional aspects. On lines 4 – 5, for example, the care worker utilises a very direct and instructional ‘It’s your turn now’, rather than a softer request or offer formulation. More significantly, this is then followed with ‘. . . going to take you to the toilet and just check your pad’, spoken in front of Len and her other friends. This combination of directness and disregard for norms, which in a conventional social situation would probably have been unacceptable, served to emphasise the institutional nature of the encounter. However, rather than simply refusing to comply, Olive is in fact able to use a more cunning (and punning) approach that relies on continuing to treat the interaction as a reciprocal one set in a normal social context (where requests are made), rather than an institutional one (where instructions are issued).

Olive’s first response (line 6) is to simply disregard the incongruous nature of the care workers approach and say ‘. . .whu-hh: I just had one’. When the care worker persists, she gives a response which further emphasises her orientation towards the social rather than institutional arena; she says (line 12) ‘I’ve got somebody with me’. She then takes advantage of some loud talking and singing nearby which masks the care worker’s next turn and

engages in a sub-routine where she 'mishears' toilet as parlour, an interactional resource which disrupts the care worker's flow. The sequence subsequently continues in a stepwise escalation of turns until Olive says categorically (line 33) 'I *really* don't want to go'. Although the care worker essentially orients to an institutional norm by being direct in displaying what is required of Olive, she is not in fact forcibly taken to the toilet, and the careworker is obliged to maintain a display of 'social' rather than institutional discourse.

Conclusion

Bakhtin's vision of carnival [...] is finally about freedom; the courage needed to establish it, the cunning needed to maintain it, and – above all – the horrific ease with which it can be lost.

(Holquist, 1984: xxi)

We have argued in this article that neither the dominant biomedical model of dementia, nor its psycho-social alternative provide a sufficient account of the complexity of communication by and between people with dementia and those who care for them in formal group care environments. In particular such models tell us little about the resources drawn on by people with dementia as social actors in order to make sense of the situations in which they find themselves, or to resist the ways in which they are constructed by others.

In the course of the three studies outlined in this article we were privileged to spend large amounts of time with people with dementia in the environments where they spend their days, and the theory advanced in this article has emerged from in-depth encounters over a number of years. As 'flies on the wall' we have no doubt been party to many interactions that would simply be missed by less immersive research methods. We have not, however, found the participants in these studies to be either the hapless victims of disease, or the psychologically needy recipients of care who populate familiar accounts of dementia. On the contrary, we have found numerous examples of the 'courage, fortitude, humour and cunning' that Benjamin (1970: 246) suggests are gained in the struggle against oppression.

To date the emergent socio-political model of dementia has not drawn to any great extent on relevant inter- or trans-disciplinary fields. In this article we have identified the work of

Mikhail Bakhtin as having particular relevance for the interpretation of our findings. The concepts of the carnivalesque, dialogism, heteroglossia and polyphony seem to us to have much to offer this field. We do not, however, wish to impose closure on the analysis of this data, nor do we suggest that Bakhtin's work is the only source of theoretical value. Rather, we wish to see more theoretically-informed debate on this subject.

We believe that studying the communicative strategies adopted by people with dementia in order to keep dialogue alive, against odds which are often heavily stacked against them, are instructive. In this way we may learn to reconstruct people with dementia as social actors, meaning-makers and partners in equal dialogue; the 'laughing people' described by Bakhtin (1984) who have always, collectively if not individually, prevailed in the face of adversity.

Table 1

Transcription symbols

In CA, punctuation symbols such as full stops, commas and question marks etc., are used to denote the characteristics of ongoing speech and do not necessarily maintain a conventional grammatical function. The examples in this article have been simplified for clarity, but the meanings of the symbols that have been used are:

xxx - underlining indicates emphasis on a word (not necessarily a rise in volume).

.

- full stops are used to indicating a falling intonation.

,

- commas indicate continuing intonation.

(0.5) - numbers within brackets indicate timings in whole and tenths of a second.

(.) - a full stop within brackets indicates a 'micro pause' of less than two tenths of a second.

:

- indicates a drawing out of the sound (can be multiple to indicate a longer sound, i.e. 'go:::')

[

- Square brackets are used to denote overlapping speech, so if, as is common in conversational speech, one person anticipates how the other's turn will end and begins their turn before it is fully complete, the transcript would look like this:

1 Sam: Would you like a cup of [tea,

2 Jan: [Yes, I'd love one

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