

# 9 The Narrative Dispossession of People Living with Dementia: Thinking About the Theory and Method of Narrative

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## Introduction

*In the beginning ...*

*Once upon a time ...*

*This is the story of ...*

*That's a good story ....*

*And they all lived ....*

*Let me tell you a story ....*

Narrative, it seems, is all around us. Bruner (2002) states that we are 'constantly in the process of making narratives' (p.3) and that narrative is so much part and parcel of life that 'human society cannot run without it'. In everyday life we recount stories about ourselves and others and in so doing both represent and construct ourselves. We are the heroes and heroines of our own stories and occasionally of the stories of others. Our experience, lives and Selves are storied. In academia narrative has also found a place not only in the humanities but also in the social sciences and even the natural sciences. It would seem there is no escape from participation in the narrative enterprise - it is a way of experiencing, relating, thinking and, ultimately, being in the world. Narrative, as Barthes (1977) said, 'is simply there, like life itself' (p.79).

To be sure, the development of narrative as a theory and method has brought (or constructed) insights into all manner of things. Narrative, emerging as it did from an interest in the experience of powerlessness (MacKinnon, 1996), was seen as a means of giving voice to those previously at the margins and has effectively, and prolifically, expanded our understanding of what it is like to be marginalised, oppressed, victimised, ignored and silenced. But even as this is so, it is my contention, *contra* Barthes, that narrative and the process of narration (narrativity) as we currently conceive and operationalise it excludes certain individuals and groups of people, creating people without narrative. These people are those I shall call the 'narratively dispossessed'. In the first part of this paper I will seek to outline what I mean by this and work

towards a tentative definition. In the latter part I will attempt to suggest some ways in which we might try to think about narrative/narrativity somewhat differently so as to narratively 're-possess' these individuals and groups.

### **A Note About Narrative**

Narrative is a general term that encompasses many genres and media. But this 'almost infinite diversity of forms' (Barthes, 1977: 79), is recognisably narrative because of certain structural features that distinguish it from other forms of recording events such as annals. I want here to focus on just three such structural features, features that I believe are currently central (though not exclusive) to the conceptualisation and operationalisation of narrative/narrativity: narrative agency; narrative consistency and coherency; and, emplotment. Although these features are inextricably interwoven I will explore each in turn, attempting to illustrate how people may be unable to engage narratively with others and the world because of the way that narrative/narrativity have been constructed. As such, I have chosen the experience of people living with dementia as a possible template that might, with due accord for the uniqueness of experience, be applied to others, such as those experiencing amnesia, autism, stroke and severe mental illness.

### **Narrative Agency**

A fundamental aspect of narrativity is being able to tell one's story. This narrative agency depends upon:

- a) being able to express oneself in a form that is recognisable as a narrative, even if one's linguistic abilities are limited (see Booth and Booth, 1996; Goodley, 1996);
- b) having the opportunity to express oneself narratively.

To express oneself narratively requires a degree of conformity to narrative rules or habits or customs. Adherence to such rules, habits, customs might vary in degree but it becomes apparent that beyond a certain threshold 'differences of degree effectively become differences of kind; beyond that point a sequence may begin to display so little narrativity that it can no longer be processed as a story at all' (Herman, 2002: 100). Consider the following from Herman (2002):

1. *A bad man walked in. Then a beneficent sorcerer pulled the lever, and the bad man was instantaneously inebriated.*

2. *A splubba walked in. A gingy beebed the yuck, and the splubba was orped.*
3. *Oe splubba fibblo. Sim oe gingy beebie ca yuck, i ca splubba orpa.*

The first of these is easily and straightforwardly recognisable as a narrative. The second, while unintelligible in terms of what actually happened and to whom or what, is recognisable as a narrative: first this happened, then that. The third displays zero narrativity because it 'lacks sufficient grammatical structure for recipients to infer actants and entities populating a story world' (Herman, 2002: 102).

For those living with dementia the difficulties encountered with expressive language and loss of memory for recent events and disorientation to place and time may limit the possibility of engaging narratively with the world and with others. Utterances may appear to others as lacking in meaning due to the person's difficulty retrieving the correct word from memory or difficulty putting words in the correct sequence along with the mis-identification and difficulty retrieving the characters, events or context. If one expects a higher degree of conformity to narrative rules, habits or customs, then it is possible that one would see people living with dementia as losing narrative agency sooner rather than later.

The second element of narrative agency is having the opportunity to express oneself narratively. People living with dementia, however, find themselves narratively constrained in two ways. First, opportunities for narrative expression are limited: people living with dementia may experience a loss of control, in that decisions are made for them (and stories made about them) as they are increasingly defined as lacking capacity and a loss of narrative opportunity because of lessened opportunity for social interaction. Second, the mental space within which narratives can be told is constrained through the mobilisation of the meta-narrative of dementia which defines the person in terms of decline, loss and fragmented cognitive functioning (and thus less able to tell a recognisable narrative) and the recuperation of expressions of agency (such as 'wandering', 'challenging behaviour', fidgeting) as symptomatic of the dementia itself (see Kitwood, 1997).

### **Narrative Consistency and Coherency**

A second feature of narrativity is a sense of consistency and coherency that holds together (more or less tightly) the events, characters and context in an understandable whole. For example, Polkinghorne (1995) suggests that there should be historical continuity of characters because such continuity enables the reader to understand the characters as individuals, acting upon, but not determined by, their history. By paying attention to the context and

embodiment of the protagonist and to the significant others in the story a successful narrative establishes a backdrop against which to evaluate the narrative. The story emerges from this backdrop in a way that does not disrupt one's belief in, or jars with the backdrop, a disruptive episode which does not appear to link with past or future. Furthermore, the choices and actions of the protagonist should make sense against this backdrop and cohere with what we know of the protagonist. In other words, for a narrative to be successful, the historical continuity of backdrop, story and protagonist is maintained.

People living with dementia, however, may not display such narrative consistency or coherency. Events may be forgotten or remembered only partially or erroneously; characters may be forgotten or mis-remembered and the context of the story being told may not always be the expected one. So, a long dead character may appear alive, well and functioning in the narratives of people living with dementia because the person living with dementia has forgotten the death of that person; sons may be remembered as husbands or not recognised at all; and the story being told might not be consistent with the context or other stories previously told. In such circumstances the accounts of people living with dementia may well appear confused, contradictory, irrational or unintelligible and as such, may not be acknowledged as narratives at all.

### **Emplotment**

Emplotment is the process whereby events, characters and context are positioned in relationship to one another in such a way that the story moves from one position to another. This formulation of a narrative trajectory, realisable through time, is essential to narrative and is dependent upon consistency and coherency. The difficulty this poses for people living with dementia is that not only may events, characters and context become confused (see above) but the forgetting of the nature of things and the loss of memory and sense of time makes it far more difficult to emplot a story. Living progressively in the present with gaps in short-term memory and little conception of the future, it is hard to envisage how people living with dementia might construct a meaningful narrative. I thus come to the definition of what it means to be narratively dispossessed - a person (or group of people) is narratively dispossessed when it is not possible to construct a recognisable narrative because of the way recognisable narratives are conceived and the means of constructing such recognisable narratives are denied to that person (or group).

## **Dementia and Narrative**

Given the impact of the onset and progression of dementia on narrativity it is easy to see how and why people living with dementia come to be seen as having 'lost the plot'. Losing the plot is, however, a serious matter if, as some believe, we are essentially narrative beings. If life is narrative, if we construct our Selves narratively, then losing narrativity (agency, consistency and coherency, and emplotment) has severe implications for our sense of Self and our being in the world.

In ceasing to be, or to be viewed as, narrative beings, people living with dementia are, in some ways, akin to Pirandello's six characters in search of an author. Their lives, having been set in motion through narrative activity, can no longer progress because there is no author to give them narrative reality, trajectory or structure. This, of course, does not mean that there is no narrative to be constructed for, as the Father in Pirandello's play says: "It [the book] is in us! The drama is in us, and we are the drama. We are impatient to play it. Our inner passion drives us on to this" (Pirandello, 1921: Online).

My concern in the rest of this chapter is to reflect on how we might re-conceptualise narrative agency, consistency and coherency and emplotment so as to facilitate narrativity on the part of those people who are narratively dispossessed because their stories cannot be told within the current way of conceptualising and operationalising narrative as a means of accessing, understanding, creating and maintaining lives and identities.

## **Re-Configuring Narrative Agency**

I want to suggest three ways in which we might think about reconfiguring narrative agency to include those who cannot currently engage in the narrative enterprise. The first is to seek to narrativise other symbolic means of expression. Stories can be articulated, for example, as much through dance, movement and artistic expression as they can language - if we as readers are sensitive enough to the narrative features of such media - and this is, of course, a familiar and common approach in the arts. Similarly, Downs et al. (in press) cite literature from Norberg and colleagues demonstrating the effectiveness of communication styles including affirmation, confirmation and communion. They also cite the growing use of sound, music, dance and movement in making contact. Observational methods such as Dementia Care Mapping (see review by Brooker, 2005) encourage us to adopt an empathic stance to our understanding of a person's experience throughout the day. Second, we look towards the joint authorship of narratives where the narrative process is shared by people living with dementia and those around them. This may take the form of co-construction of narratives (see Keady and Williams, 2005, Williams and

Keady, 2005) whereby the final narrative is very deliberately and consciously a negotiated product between those people living with dementia and others or the piecing together and progression of the fragmented narratives of people living with dementia by those who support them:

The person with moderate or moderately severe dementia may be able to present only fragments of a performance story. The more a nurse knows about narrative components or the different sections of a story, the more easily he or she can identify and follow up on a story fragment offered by a person with dementia.

(Moore and Davis, 2002)

The third way to reconfigure narrative agency is to examine the contribution made by people with dementia to the narratives of others. This, in good part, is to understand the nature and role of reading in the process of narrativity. Illich (1996) in commenting on Hugh of St Victor's *Didascalion* differentiates between monastic and scholastic reading. Scholastic reading, he says, views the text as an object to be debated (What is the author saying here?) while monastic reading was an embodied activity that viewed the text as having something to say directly to one's experience and existence (What does this text say to my life?). It is my contention that by viewing the text of another's life in this latter fashion we are opening the door to re-establishing some degree of narrative agency through contributing in a meaningful fashion to our own life narratives.

### **Reconfiguring Narrative Consistency and Coherency**

The narratives of people living with dementia may at times appear to be fragmented, inconsistent and incoherent. This, however, may be seen as a function of an insistence on linear consistency and coherency rather than as inherently associated with dementia. We might, for instance, choose to reconfigure consistency and coherency to accommodate a sort of patchwork of fragments, individually uncertain in meaning or narrative value, into a meaningful whole. Moore and Davis (2002) refer to this as narrative quilting. Stories are thus related, not necessarily to what immediately preceded them but to others stories that have been told by or about the person living with dementia. The narrative consistency and coherency then rests not in chronology but in the assemblages of fragments related by meaning. The accurate reading, and meaningful assembly, of such fragmented stories requires the sort of narrative competence that Montello refers to when discussing the benefits of engaging with literary narratives (Montello, 1997): "joining one story with another, accurately to observe and make sense out of the chaos of suffering and loss" (p.194).

### **Reconfiguring Emplotment**

Our final reconfiguration centres around the notion of emplotment. I want to suggest that rather than insist on a narrative trajectory that is maintained over a reasonably lengthy period of time, we focus on what Bamberg calls 'small stories', stories that privilege the fleeting and fragmented as contributing to the performance of identity in everyday interactions (Bamberg, 2004). Given the 'present-ness' of people living with dementia, such a focus would seem to be highly appropriate and, from Bamberg's work with adolescents, an effective means of recognising, acknowledging and supporting the creation and maintenance of Selves through the minutiae of everyday life. What is required is the ability to skilfully read and collect such small stories over different times and places so that they may be knitted into patterns that can be used to support the personhood of the person living with dementia. Emplotment thus becomes a process of assembling, over time, small stories that are related to one another in terms of expressions and developments of the Self in the face of changing circumstances. Linear emplotment thus makes way for thematic emplotment.

### **Concluding Remarks**

The onset and progression of dementia threatens narrative abilities through its effect on language and cognitive function. Opportunities for narrativity may also be limited by a decrease in social interaction or the response of others who unnecessarily take over the narrative function or who recuperate attempts at narrative expression (such as 'wandering', 'challenging behaviour' and fidgeting) as symptomatic of the dementia. But the narrative dispossession of people living with dementia can also be seen as a function of how we conceptualise and operationalise narrative and narrativity. The focus, or insistence, on linear consistency, coherency and emplotment, coupled with a one-sided approach to narrative agency may also serve to dispossess people living with dementia from their (potential) narratives. In this paper I have attempted to indicate both how this is so, and how we might start to think about reconfiguring narrative agency, consistency and coherency, and emplotment so as to include and empower people living with dementia.

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