Narrative(,) citizenship and dementia: The personal and the political

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**Abstract**

Much has been written about the centrality of narrative to an understanding of the person. The basis of the argument put forward in this article is that narrative and narrativity are centrally constitutive of the personhood and the Self. This being said, the current conceptualisation of narrative and narrativity excludes some individuals and groups of people, such as people with dementia. Relatively recently there has been a move toward developing a citizenship model of dementia as a framework within which people with dementia can be empowered. This development is, however, currently under-theorised. The argument presented here is that in order to develop that model we need to find ways of integrating narrative and citizenship, thus linking the personal and the political.

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__Let me tell you a story__

With those few words we are hooked. We give our attention, we want to know. We want to know who these people are, what they do and why they do it. We want to know what happens next. With those few words we are brought into a relationship with characters and events. Who are the heroes? Who are the villains? Is it a tale of derring-do, a tragedy or a comedy? Will it all work out well in the end? Of course, we might decide that the story is poor or poorly told. We might think the characters weak or unbelievable or the plot thin. The genre may not fit our mood or our taste. We might finish listening before the story-teller has finished telling. All of these things may happen but that does not take away the power of the initial words.

__So let me tell you a story__

Once upon a time there was a land where story-telling was all there was. The world had been brought into being by the power of stories and the people there not only told stories but were the stories that they told about themselves and about others. But not only individuals, organisations and institutions had stories. Medicine, the Law, economics, politics, government, social science, even Science were all made up of stories.

In this land lived an elderly woman. The stories she had to tell were of having lived an ordinary life. Her stories were not powerful or famous. Her stories hadn’t changed the world. At least not on a big scale. She had lived her life and told her stories as most of us do — among a small circle of people, her family, friends, work colleagues and acquaintances. Occasionally she had told her stories to a slightly wider audience. But they weren’t the stories that made the news or big budget Hollywood movies. But when she said, “Let me tell you a story”, those around her knew they were about to hear something worth listening to. From her stories her children and her grandchildren learnt to discern right from wrong, what it meant to belong, how to tell their own stories, what it meant to be a story-teller and a story told. Their worlds, their stories were transformed by those few little words, “Let me tell you a story”.

But as she grew older this woman found that there were fewer and fewer opportunities to tell her stories. Audiences were harder to find and harder to engage. And the stories that others told about her were constraining, hurtful, oppressive. In these stories she was part of a demographic time bomb, a drain on resources. In these stories her future was one of decline and decrepitude. And it was said that the older she got the more likely it would be that she would forget her stories, in other words forget her Self. It was even possible that she would be removed to another place where individuals’ stories were not valued, where people lost their voice and the only
stories that they heard were the stories of those in charge and of the place itself.

The woman was scared. She didn’t want her story to end like that. Not only was it not a happy ending but it didn’t make sense. Her stories had always been ones of hope, empowerment, meaning. Her stories had been ones of contribution, helping, relationships. This future, the one being laid out for her by others, did not emerge from her story so far. It was as if there had been a fissure, the emergence of a chasm that once crossed would forever separate her from her past.

The more the elderly woman thought about this, the more she felt scared. Scared but also angry. “Who are they to say that this is my story?” she found herself asking. “WHO ARE THEY TO SAY THAT THIS IS MY STORY?” she found herself shouting. She was determined to fight back. She was determined to tell a different story and to change the stories of others. But not only that, she was determined to change the way stories would and could be told. The story would not be a tragedy but a tale of derring-do.

Introduction

That, in essence, is my argument in this chapter — that we are indeed narrative beings who find our Selves in the stories we tell about ourselves and the stories that others tell about us; that narrativity is essentially an inter-personal activity; that some people find their stories marginalized, themselves as narrators dispossessed; but that it does not have to be that way. The stories we tell, as Ewick and Silbey (1995) argue, can subvert the status quo and open the door to new ways of telling, and thus new ways of being. I will develop this argument through the lens of the experience of people with dementia, though it has been argued elsewhere that people experiencing severe mental illness may also be narratively dispossessed (Baldwin, 2005, 2006a) for the same reasons as given here. I will further argue that what is needed is not simply an appreciation of the stories of others but a ‘narrative citizenship’ that is given structural and organisational form. We may be seeing elements of this narrative citizenship emerging but there is still much to be done if people living with dementia are to be narratively repossessed and thus become narrative citizens.

A brief note on narrativity and personhood

The view that we are narrative beings is well-argued by authors such as MacIntyre (1984), Bruner (1987) and Taylor (1989). For these authors, among others, not only do we exist in a story-telling world but our very Selves are constituted by the stories we and others tell about ourselves. Our experience (of both the world and ourselves) is not reality given narrative form but rather our narrative form made real. In other words, we are our stories — to be unheard, unrecognised, unremembered is absolute death (Bakhtin, 1984). In these stories we constitute ourselves as persons in accordance with concepts of ourselves (Blustein, 1999). These self-concepts are not static (Blustein, 1999) and our identity is a combination of historical narrative and literary fiction (Ricoeur, 1987). The importance of narrative in the construction of identity is also becoming recognised in the field of dementia (Mills, 1998; Vittoria, 1998; Surr, 2006).

What flows from this is that narrativity – and thus personhood – is a performative activity. Such activity requires agency and opportunity. People with dementia, however, may be denied these; denied agency through the way we currently conceptualise what constitutes narrative and narrativity (see Baldwin, 2005, 2006a); and denied opportunity through institutional arrangements and practices that restrict social networks (see Baldwin, 2006a).

From patient to citizen: changing models in understanding dementia

The historical model for understanding dementia has been the medical model of cognitive deficit. This model defines dementia solely as a neurological condition and focuses on deficit and impairment. In this model persons with dementia are first and foremost ill, the prognosis poor and management consists of the observation of decline. This view has been exacerbated by the lack, until relatively recently, of any effective treatment and even now the possibility of treatment is uncertain.

Kitwood (1997) challenged this model, arguing that dementia was not solely a medical condition but a composite of bio-social–psychological factors, uniquely constellated in an individual’s life. In re-conceptualizing dementia in this way Kitwood was implicitly acknowledging the distinction made by the disability movement between impairment and disability, impairment being the result of neurological changes and disability ‘the disadvantage or restriction of activity caused by contemporary social organisation’ (UPIAS, 1976: 3). For Kitwood (1997) people with dementia were not only disadvantaged by the environment but also by the attitudes and actions of those around them, disadvantages well understood in the field of disability (see, for example, Oliver, 1990; Barnes, 1996). Examples of such disabling social environments in relation to dementia would be the lack of adequate or appropriate signage contributing to the confusion of persons with dementia, or the lack of meaningful activity in some residential homes in which persons with dementia are essentially warehoused until death. Dementia as disability has been directly addressed by authors such as Gwilliam and Gilliard (1996), Marshall (1998), Pollock and Bonner (2000), Downs (2002) and Adams and Bartlett (2003), although it would probably be fair to say that the disability model of dementia is still relatively under-theorised.

The under-theorisation of dementia as disability notwithstanding, more recently there has been a move towards developing a citizenship model of dementia. In an excellent paper, Bartlett and O’Connor (2007) argue that although “the idea that people with dementia have rights has long been recognized” citizenship has rarely, if ever, been explicitly applied to people with dementia. They go on to argue that “in broadening the conceptual lens [to embrace citizenship], dementia studies will be in a better position to progress, and to understand people’s experiences of dementia, particularly experiences related to discrimination”. The need to develop a citizenship approach to people with dementia emerges from the limits of the personhood approach: that the approach has promoted and individualised lens for understanding the experience of dementia, that it does not necessarily promote the vision of someone with agency and that personhood is an essentially apolitical concept.
A citizenship model, in contrast, focuses on issues such as social inclusion, power, and citizenship as practice. Bartlett and O’Connor then discuss ways in which people with dementia are realising their citizenship through advocacy and self-help groups and user and carer participation in research. Indeed, it might be argued that the Mental Capacity Act (2005) goes some way towards establishing the citizenship of people with dementia by the assumption of capacity and the requirement that every effort must be made to involve them in decision-making processes.

Where I depart from Bartlett and O’Connor is in what appears to be their too rigid distinction between personhood and citizenship as two approaches to dementia care. This over-rigid distinction is, I think, a function of their favouring the concept of ‘intimate citizenship’ as developed by Plummer (2003) – that is, a focus on inter-personal relationships – and backgrounding the relationship of the person with dementia with the nation state. To my mind, the personal, inter-personal and the institutional/structural are inter-related through the stories we tell and are told about us, whether by individuals or collectivities (such as the Law, businesses and government).

The relationships between the personal, inter-personal and the institutional/structural are evident in three ways.

First, subjectivity is central to citizenship because “it requires the subject to position itself in relation to something outside of it — an idea or principle, or the society of other subjects” (Somers, quoted in Hearn, 2004: 381). In this we approach something akin to Bakhtin’s dialogic self but whereas Self and other in Bakhtin is usually taken as the individual’s relationship with other individuals (see Barresi, 2002), here the concept is expanded to include ideas or principles. In other words, individual subjectivity – as manifested through narrativity – is positioned in relationship to inter-personal and institutional/structural ‘Others’.

Second, citizenship relates to our own existence, our sense of belonging in and contributing to society and thus ‘[t]he legal, political, and social rights of citizenship are embedded in social relationships and everyday activities’ (Powell & Edwards, 2002). As personhood as narrative performance arises in, and is dependent upon, social relationships and everyday activities, it is thus inextricably linked to the concept and practice of citizenship.

Third, collective narratives, often realised in social policy, create the space within which individuals exercise their citizenship rights. In so doing, they also create formal representations of identity — for example, what constitutes the formal representation of an aging identity (see Powell & Edwards, 2002). In so doing, policy narratives define the space in which individual identities can be legitimately performed (Powell & Edwards, 2002). These definitions and spaces may, of course, not be the ones that the individuals so defined and bounded would choose for themselves — our elderly woman in the opening being defined as a burden in the face of her experience (for other examples see Plummer, 1995 on sexual stories and McRuer, 2006 on crip theory).

In conceptualising citizenship in this way, the links between personal and policy narratives become clear: issues of identity, belonging and social relationships are inherent to both (for examples of links between personal and policy narratives see Mullen, 1999; McDonough, 2001; Sharf, 2001). Being inherent to both, however, does not mean that they encapsulate shared purposes, understandings, concepts or meanings and thus tension can arise and competing narratives can be constructed. The tension between individual narratives and those of the collective (policy narratives) raises the question of how narratives interact — and to help understand this narrative interaction I want here to introduce to develop what Plummer (1995) calls a ‘sociology of stories’, a way of understanding the roles of stories and the work they do.

**A sociology of stories**

In Telling sexual stories Plummer (1995) outlines what he calls a ‘sociology of stories’. This sociology, which focuses more on the structural–functional elements of story-telling and goes beyond the usual limits of exploring narrative as personal and inter-personal performative activities — important as these explorations are — and links narrative into a wider sociology that can account for both the narrative construction of personhood and the citizenship issues of power, social inclusion and agency. This sociology consists of five areas: the nature of stories, the making of stories, the consuming of stories, the strategies of story-telling and stories in the wider world.

The nature of stories addresses the issue of whether a particular narrative seeks to empower and facilitate or to degrade, control or dominate another. For example, some stories, such as the narrative of people with dementia losing their personhood, degrade and dominate the narratives of people with dementia through focusing on cognition as constitutive of personhood. An example of this can be found in Brock (1993) where he states that: ‘The dementia that destroys memory in the severely demented destroys their psychological capacities to forge links across time that establish a sense of personal identity across time. Hence, they lack personhood’ (p.373). This is a disabling meta-narrative (see Nelson, 2001) in that it focuses only on one aspect of being human (cognition) and on this basis justifies restricting health care resources available to those who do not meet the narrow criteria for inclusion in the personhood club. This meta-narrative is, however, being transformed by the work of such authors Kitwood (1997) who view personhood more holistically (see also Baldwin & Capstick, 2007) and Sabat and Harré (1992), Post (2000), Klein, Cosmides, and Costabile (2003) and Surr (2006), among others who argue for, and cite empirical work supporting, the survival of the self in dementia.

The making of stories deals with the strategies that are employed in order to tell one’s own narrative and to silence others. While probably not a conscious strategy to silence people with dementia, the narrative that it was impossible to access the experience of dementia because people with dementia were unable to communicate served to exclude people with dementia from contributing to more constructive narratives. In this context it is interesting to note that that in the Forget me not 2002 report (Audit Commission, 2002) reviewing progress in mental health services in the UK, people with dementia are not listed as having been consulted.

In more recent years the negative view of the capabilities of people living with dementia has been increasingly successfully challenged (see, for example, Wilkinson, 2001; Proctor, 2001) with people living with dementia increasingly...
finding both a voice and a narrative space. People living with dementia are beginning to find their voice through such channels as the development of the Dementia Advocacy and Support Network International website (http://www.dasinternational.org) and the movement on the part of the Federation of Quebec Alzheimer’s Societies to abandon the term dementia in favour of more accurate and less stigmatising medical terminology (see Girard and Ross, 2005). In research, the voice of people living with dementia is increasingly heard.

The consuming of stories involves issues of who has access to particular narratives, whether such stories are widely available or restricted to narrow groups and whether access to stories is extended or curtailed. In terms of dementia, the stories of people with dementia have, historically, not been heard and even when attention has been given to these stories, the audiences for such stories have been individuals (such as through life histories as part of care plans) rather than organisations and institutions (as part of the policy process) For example, the Forget me not report referred to above in excluding people living with dementia also acted to restrict the audience for people living with dementia who were beginning to find their voice. In other words, those toward whom the report was directed were denied the opportunity to hear the narratives of individuals with dementia.

The strategies of story-telling examine the ways in which narrators employ certain devices in order to open up their own story and close down alternative voices. For example, in the guidelines recently issued by the National Institute for Health and Clinical Excellence (NICE, 2006) the scene is set for a particular position on dementia in the following statement: ‘As the condition progresses, people with dementia can present carers and social care staff with complex problems including aggressive behaviour, restlessness and wandering, eating problems, incontinence, delusions and hallucinations, and mobility difficulties that can lead to falls and fractures.’ The linking such behaviours with neurological problems forestalls any discussion of other causative factors – for example, aggressive behaviour might be provoked by the frustration of dealing with staff who are perceived as being unreasonable and intransigent – and thus opens up the space whereby the story of interventions (whether pharmacological or not) focuses on the individual rather than the relational. In so doing, a narrative of a more dialectical approach to dementia and dementia care is forestalled (see Baldwin & Capstick, 2007).

Again, in dementia, these strategies are unlikely to have been conspiratorial plays on the part of people without dementia but indicate how taken-for-granted assumptions and approaches open up spaces for some narratives and close down such spaces for others.

Finally, stories in the wider world, seeks to address how “Some voices – who claim to dominate, who top the hierarchy, who claim the centre, who possess the resources – are not only heard much more readily than others, but are also capable of framing the questions, setting the agendas, establishing the rhetorics much more readily than the others” (Plummer, 1995: 30). In the past, the questions and agendas in the field of dementia have been set predominantly by scientists and health care professionals. With the development of the carers’ movement (primarily in the form of the Alzheimer’s Society) the voice of carers began to be heard and is, now, particularly strong in terms of campaigning and research. However, while things have improved with regard to hearing the voice of people with dementia in research (see, for example, Downs, 1997; Proctor, 2001; Wilkinson, 2001; Moore & Hollett, 2003; Keady & Williams, 2005) people with dementia are still not at the forefront of policy making.

**Narrative citizenship**

It is at this juncture I want to return to the deliberate ambiguity built into the title of this chapter by placing the comma between narrative and citizenship in parentheses. So far I have drawn attention to both narrative and citizenship and, hopefully, indicated the links between these two concepts (and practices). From this point on, I want to remove that comma and to develop the concept of *narrative citizenship*, outlining what narrative citizenship might mean in practice.

**Narrative agency**

The starting point for the development of narrative citizenship is the maintenance of narrative agency, a fundamental aspect of narrativity being the ability 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 & Booth, 1996; Goodley, 1996);

b) having the opportunity to express oneself narratively.

I want to suggest three ways in which we might think about narrative agency so as to include people living with dementia 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, Small, and Froggatt (2006) indicate the communicative possibilities of sound, music, behavioural cues and mirroring and observational techniques such as Dementia Care Mapping (Bradford Dementia Group, 2005) can provide us with some insight into the journey of individuals in context 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 & Williams, 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 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.

In arguing for the above, I am aware that people living with dementia are more dependent on the narrative literacy of others than perhaps are those of us who do not live with dementia. Narrative agency needs to be both actively facilitated and constructed in a way that is not so for people whose agency is not in question.

“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 & Davis, 2002: 263, my emphasis).

This narrative literacy would involve the development of skills in examining the types and roles of narratives in the life of the person with dementia and looking to the construction of meaningful narrates for and with that person. For example, a narrative approach to the palliative care of persons with dementia might ask what narratives are in play in the situation (personal, institutional, discoursal), what the desired narrative trajectory is and how the chosen narrative maintains and develops the Self (see, Baldwin, 2006b for a description of what a narrative approach to palliative care might look like).

The second part of narrative agency is having the opportunity to express oneself narratively. It has been argued (Baldwin, 2006a) that the opportunities for narrative expression for people living with dementia are limited, both by institutional arrangements and personal actions. Narrative citizenship would require, at the very least, an intention to maximise the opportunities for narrative expression — for example, on a personal level through the generation of life histories and advanced communication between people living with dementia and staff (catching the small stories of a person with dementia. 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 & Davis, 2002: 263, my emphasis).

Policy narratives

Policy statements have not generally taken people with dementia as their specific subjects (Cantley, 2001) and it is only recently that there has been any legislation dealing specifically with dementia (see, Jones, 2001; Mental Capacity Act, 2005). While current official documents (for example, Audit Commission, 2000; Department of Health, 2001) are improvements on those of the past, they are still dominated by a bio-medical model of dementia. This domination serves to limit both the contribution of people living with dementia to the policy process and their opportunities for narrative expression. While not suggesting that we disregard the neurology involved in dementia, neurology is not the only (or even necessarily the most important) factor in dementia. Kitwood provided a model of dementia care called the Enriched Model (see Brooker & Surr, 2005) that understands the experience of dementia as being determined by how neurological impairment, health and physical fitness, biography/life history, personality and social psychology are uniquely constellated in a person’s life.

Social policy, therefore, needs to be reconfigured around wider factors than biomedicine if we are to truly include people with dementia in the policy process:

“The lives of people with dementia are affected by an enormous range of health and welfare policies as well as wider policies that shape the communities in which they live” (Cantley & Bowes, 2004: 267).

In being reconfigured, focus might be given to generating meta-narratives of dementia in opposition to that of the biomedical meta-narrative of deficit and decline:

“…the citizenship model … suggests that people with dementia have a unique contribution to make to our society … Many people with dementia go through a period of great creativity if they are given the opportunity to express it. Other contributions such as emotional veracity and humour, as well as an example of fortitude in the face of major trauma, are often undervalued” (Marshall, 2005: 18).

Policy could be based on focusing on the strengths and retained abilities of persons living with dementia and a rehabilitative view of dementia (see, for example, Mountain, 2005). If we are to take seriously the idea of a citizenship model of dementia we must be aware of how “master narratives of the … community are used to constitute an identity according to the requirements of an oppressive group” [in this circumstance, the non-cognitively impaired] and how “Group members are not only deprived of opportunities to enjoy valuable roles, relationships and other goods on offer in the society, but often also come to operate, from their point of view as the identity requires” (Nelson, 2001: 187). In so doing it is possible to address some of the issues raised by Plummer (see above) in facilitating the stories of people with dementia, providing a wider audience for those stories and embedding those stories in the wider world.

Policy narratives are also (or can be, if not should be) narratives of social inclusion, establishing spaces in which identities of belonging and participation are both desired and encouraged. By aligning the social space in which possible identities are realised with the experienced, lived narratives of people living with dementia, we strengthen both personal and policy narratives, enhancing social inclusion and the sense of self. Citizenship and self move closer together.

Linking the personal and the political

But this moving together is not an automatic outcome of more inclusive policy narratives. The link between the personal and the political has to be made concrete through
the provision of services and resources (see Hughes, 2003). For example, currently there are few independent advocacy services for people living with dementia. Consequently, in expressing their views people living with dementia are often reliant on their family carers. While this may not be necessarily problematic, it may be so as people living with dementia and their carers may have different interests and family carers may not have the specialist knowledge and skills to navigate their way through oft-times complex and non-transparent processes. Independent advocacy services would circumvent these potential difficulties, giving focused time and space to people living with dementia to develop their own narratives.

Similarly, the nuances of narrative literacy are skills that need to be developed through training and practice – with concomitant resource implications – rather than skills that are assumed or left to individual practitioners. Structures for personal and professional development should include training in narrative sensitivity. This is something that has been recognised in the practice of medicine (see, for example, Charon, 2004) and something that could and should be extended to the practice of dementia care.

Time is another consideration in accessing the narratives of people living with dementia. It is generally accepted that communicating with people living with dementia may take longer than communicating with others, because of the nature of the impairment. Kitwood (1997) referred to outpacing as one factor in malignant social psychology that undermines the personhood of the individual. The often relatively short periods allocated by government for consultation on policy documents militates against full inclusion of people living with dementia (Consider this also in the light of the general absence of advocates). Policy development needs to take account of the experience of time for people living with dementia.

Reconfiguration of funding may also serve to encourage a more inclusive and participative approach to residential care. Currently funding is given whether residential homes provide focused person-centred care or are little more than warehousing until death (provided certain minimum standards are met). Restructuring the funding system to encourage true person-centred care and participation in monitoring, evaluating and developing services (for example, residents’ meetings and advocates) and penalise ‘warehousing’ is a matter of political will. Linked to a reform in the system of inspections, this could have a major impact on the lives of people living with dementia in residential care.

The above are only examples of what could be done structurally to facilitate the link between personal and policy narratives and are raised here to generate debate; all require both empirical work and further reflection to identify the most effective strategies of inclusion. There are likely many other possibilities, limited only by our political imagination and will).

Coda

And so we return to the woman at the beginning of the chapter. Her story is, I would suggest, typical of many older people, and people living with dementia — a story taking a trajectory that was unplanned and unwanted. But one of the advantages of viewing life as narrative is that it reminds us that it can be re-written, there is always another version of the same story waiting to be told. Being able to tell that story depends on how our story interacts with those of others and the opportunities and resources we are given to tell that story. Are we subject to constraining meta-narratives or embraced in supportive, facilitative empowering ones? Do the institutions we enter encourage personal narrative and participation in ethos and structure? Does the supporting framework of social policy and resources give incentive and impetus to new ways of engaging with people living with dementia so that they can participate as citizens? It is my suggestion that the development of narrative citizenship bridges the gap between the personal and the political in a way that individuals can say of meta-narratives: “That is my story”).

References

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