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Reconceptualising dementia friendly communities

This Knowledgeshare piece takes a critical look at the concept of dementia-friendly communities by examining how that concept, which aims to build a better place for people with dementia to live, works to conceal and overlook the social, cultural, political, and economic realities of many marginalised people's lived experiences. Drawing on knowledge from feminist social cultural theories I want to highlight some of the undisclosed subjectivities that are hidden in representations of people living with Alzheimer's and dementia and to this end suggest a more political approach that seeks to expose discrimination as a more effective way towards finding a dementia-friendly community vision. I want to start by talking through what I initially imagined as a dementia-friendly community. From there, I want to discuss how I then critiqued that vision, and through that critique how I was able to reconceptualise the vision so that it is more radical, more progressive, and more person-centred (Manley et al. 2008).

Following the work of Dewing (2006) I originally conceptualised a dementia-friendly community as a geographical space that works to raise awareness about, and ultimately normalises 'wandering' (traditionally seen as the behaviour of unsafe aimless roaming associated with people living with dementia) as a natural activity that is part of everyday life for people with dementia, and is a space that is both safe and communal. In my conceptualisation there is inclusion of dementia dogs, which provide companionship and support to people living with dementia and also help raise awareness of dementia in geographic communities. There is the presence of the voluntary sector and volunteers who work to provide support and raise awareness within communities, organisations, and work places. There are various hubs that provide information and resources about dementia, raise awareness, signpost, and facilitate encounters among people living and working within the

same communities and those with dementia. Such hubs are part of the public and private sector and exist for example, in cafes, financial services, the retail industry, libraries, GP surgeries, energy companies, the emergency services, post offices, and schools. There are also a variety of projects run by voluntary sector organisations or volunteers aimed at improved inclusion of people with dementia in the community. These activities are aimed at empowering and enabling people living with dementia and at providing engagement across the community (Dewing 2006). For example some projects might include gardening, art, sewing, singing, woodland or nature, and reminiscing through the use of memory books or boxes. All of these suggestions are remarkably aligned to the Department of Health strategy 'Improving the health of people with dementia' and the strand on 'Dementia-friendly communities' (DoH 2012). So I decided to take a more critical look at the government proposals and to think about, not what and who is included, but more crucially what might be concealed through that inclusion.

Firstly, I thought about the 'Compassion in Practice' national vision (DoH 2012) and decided to revisit the word 'compassion' and think about its etymology. The etymology of 'compassion' is Latin and means 'co-suffering', or to suffer with. It is more complex than simply having empathy. Compassion gives rise to an active desire to alleviate another's suffering and is therefore about taking social action. And whilst the current government strategy on dementia is underpinned by the notion of taking action through building communities of awareness, it is the strategy's raising awareness of an experience constructed as universal that I want to question. I want to suggest that the current strategy negates significant consideration of some of the socio-cultural subjectivities that disadvantage particular individuals in particular ways, and that a greater attendance to these could provide a far wider reaching, engaging, and transformative approach (hooks 1984).

Next I collated images under the key search terms 'Alzheimer's' and 'dementia' by conducting a Google search. I also looked at the DoH, The Alzheimer's Society, and Dementia UK's websites. I observed something significant about the images that came from the search:

- The images represented a universal picture of dementia. They culminate in the illustration of dementia as something that can, and does, affect everyone irrespective of, gender, class, race, and ethnicity. So there were as many images of men as women living with dementia, there were women and men as carers, and BAME (Black, Asian and minority ethnic) groups were equitably represented.

And yet we know that women take on the majority of caring and domestic labour responsibilities in relation to Dementia (Boyle 2013). We also know that BAME groups face discrimination every day, and we know that those from socially and economically deprived areas face barriers to health care (Issitt 1999). So the equity of experience suggested by the visual representations indicates that socio-cultural subjectivities that are lived out as experiences of marginalisation and discrimination are hidden, and this is problematic (Ahmed 2004).

Engagement with feminist intersectionality theory (hooks 1984; Lorde 1984; Min-ha 1988) can be useful in deconstructing the universal visual representations and rhetoric presented above. By understanding people living with dementia as individuals living with social, culturally, and economically subjective experiences, rather than a somewhat homogenised group defined by their dementia, works to reveal the discriminations along intersecting lines of gender, race, ethnicity, age, class, and sexuality. This offers a frame of reference from which the most vulnerable and marginalised can seek social justice and engage in forms of

resistance against the way in which they are constituted and governed (Foucault in Rabinow 1997).

For example, by deconstructing, and thinking critically about the gendered nature of women's lives would enable women living with dementia to reframe their identities. Women who have been largely responsible for domestic labour, or who are victims of domestic abuse, could find the space to subvert such governance, and in so doing reconstitute their identity. Through wandering women can reclaim outside space and resist governances around where and at what time it is appropriate for women to be in public spaces. Black, Asian, and minority ethnic people can find a platform for their stories and narratives (Griffiths 1994; Easton 1996) to act as the personal and political combined, and be able to write their own story and construct themselves in opposition to the ways in which dominate society constructs them, for example in subverting the pathologising of Othered bodies.

Audre Lorde (1984), the Caribbean-American writer and civil rights activist, said 'without community there is no liberation…but community must not mean a shedding of our differences, not the pathetic pretence that these differences do not exist' (Lorde 2007:111). Recognising that differences matter and advocating that communities engage in what feminists have called a double turn (Ahmed 2004), a turn that recognises how socio-cultural privilege perpetuates disadvantage and marginalisation, involves not only looking towards one reflection of a universalist experience defined by one subjectivity, but crucially of reorienting that gazing back towards an active engagement with multiple and interlocking social subjectivities, which would allow dementia-friendly communities to empower the marginalised, and by understanding the personal as political would potentially develop a person centeredness that moves towards more progressive transformative approaches.

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References

Ahmed, S. 2004, 'Declarations of whiteness: The non-performativity of anti-racism',
[Online], Available at:
http://www.borderlands.net.au/vol3no2_2004/ahmed_declarations.htm. *Borderlands e-Journal*, vol. 3, no. 2. Accessed 14th March 2014.

Boyle, G. 2013, 'Still a woman's job: the division of housework in couples living with
dementia' *Families, Relationships and Societies*, Volume 2, Number 1, March, pp. 5-21(17).

Department of Health (DoH), NHS Commissioning Board, 2012, *Compassion in Practice:
Nursing, Midwifery, and Care Staff Our Vision and Strategy*, [online]. Available at:
<http://www.england.nhs.uk/wp-content/uploads/2012/12/compassion-in-practice.pdf>.
Accessed 15th March 2014.

Dewing, J. 2006, 'Wandering into the future: reconceptualising wandering?*"a natural and
good thing"'*, International Journal of Older People's Nursing,* 1(4), 239-249.

Easton, A. 1996, 'Autobiography, gender, and race: Maya Angelou's *I know why the caged
bird sings*', in Cosslett, T., Easton, A., & Summerfield, P. (eds), *Women, power, and
resistance*, Open University Press, Buckingham.

Griffiths, M. 1994, 'Autobiography, feminism and the practice of action research', in
Educational Action Research, Vol. 2, No. 1, pp. 71-82, [online], Available at:
<http://dx.doi.org/10.1080/09650799400200005>. Accessed 15th March 2014.

hooks, B. 1984, Feminist theory: From margin to centre, South End Press, Boston, MA.

Issitt, M. 1999, Conceptualizing competence and reflective practice: A feminist perspective,
in O'Reilly, D., Cunningham, L., & Lester, S. (eds.) *Developing the capable practitioner*,
Kogan Page, London, pp. 187-202.

Lorde, A. 2007, 'The master's tools will never dismantle the master's house', *Sister outsider:
essays & speeches*, CA: Crossing Press, Ed. Berkeley.

Manley, K., McCormack, B., & Wilson, V. 2008, Introduction, in K. Manley, B. McCormack, & V. Wilson (eds.), *Practice Development in Nursing: International Perspectives,* p1-16, Blackwell Publishing, Oxford.

Minh-ha, T. 1988, 'Not you/like you: Postcolonial women and the interlocking questions of identity and difference', *Inscriptions,* no. 3–4, pp. 71–80.

Rabinow, P. 1997, Michel Foucault: Essential Works of Foucault 1954–1984, Vol. 1, Penguin, London.

Stanley, L. & Wise, S. 2002, *Breaking out again: Feminist ontology and epistemology*, New Edition, Routledge, London & New York.