Dementia: Stigma, Language, and Dementia-friendly

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The incidence of dementia worldwide is rapidly increasing and Alzheimer’s Disease International (ADI) (2013) reported that ‘there are 7.7 million new cases of dementia each year, implying that there is a new case of dementia somewhere in the world every four seconds’. In Australia, there are over 332,000 people diagnosed with dementia, with an estimated 1700 new diagnoses per week (Alzheimer’s Australia, 2014c). As the incidence of dementia rises globally, the rate and scale at which it is currently escalating has forced governments to make it a health priority, and from a consumer’s perspective, it is therefore very timely to re-consider the language being used to represent people with dementia and its impact on stigma. I have also considered the presence of stigma within the stigma literature, and wonder if the presence of stigma towards people with dementia, within the dementia and stigma literature, exacerbates the stigma, or prevents the timely translation of good research into better practice. Finally, I will briefly discuss the concept of a dementia friendly community, and the challenges this presents to me as a person living with younger onset dementia.

Stigma

The definition of stigma and the role it plays in defining the experience of people with dementia is well documented. Goffman (1963) refers to stigma as ‘spoiled identity’; Link and Phelan (2001) discuss it in terms of persons being negatively labelled, a loss of status and power, discrimination and stereotyping. Stigma affects a number of things when considering dementia, including the person’s willingness to seek diagnosis, to seek support once diagnosed and a lack of willingness to participate in research (Burgener & Berger, 2008; Milne, 2010; Garand, Lingler, Connor, & Dew, 2009). The care provided is also of a lower standard due to stigma within the health care profession, and services are distorted (Benbow & Jolley, 2012; Devlin, McAskill, & Stead, 2006; Milne, 2010). Stigma increases the feelings of shame (Scheff, 1990), and more recently ADI (2012) also reported people with dementia still feel a deep sense of shame. The Alzheimer’s Society of Ireland (2008) reported on two types of stigma, one as external, that is stigma towards the person, and the other as internal stigma, where the person feels shame about themselves; that they are ‘less of a person’ because of the symptoms of dementia. For timely diagnosis, more appropriate care and to improve the quality of life for people with dementia, it is essential we reduce the stigma.

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Stigma affects more than just well-being and quality of life for people with dementia and their families (Sandra, 2006). Language, inclusion and providing dementia-friendly communities are important in the reduction of stigma, and without positive change, stigma will continue to be a significant burden on people with dementia. Stigma is still a salient feature of the experience of people with dementia (Alzheimer’s Society, 2008; Buttrose, 2012; Batsch, Mittelman, & Alzheimer’s Disease International, 2012; Hodkinson, 2011; MacKenzie, 2006; Ryan, 2006), and because of this I have explored the existence of stigma within the dementia literature. It is apparent there is a lack of research focused on the effect or feeling of stigma specifically from the perspective of the person with dementia, and how stigma might be exacerbated by the use of incorrect information and inappropriate language used to describe people with dementia (Garand et al., 2009; Vincent, in DPS News, 2014). The Honourable Kelly Vincent, MLC, leader of Dignity4Disability in South Australia says, when communicating with people with disabilities, that they are the experts; so too are those people diagnosed with dementia.

I have explored stigma in the literature, looking at it in a new way by questioning whether the researchers exacerbate stigma, even though their intent is to promote positive change. Considering the lack of inclusion of people with dementia in the cohorts being studied, it is still very much ‘about people with dementia, without them’, which cannot give a true picture of the issues for this group, also serving to reinforce the stigma. Caregiver stigma has been explored often (Alzheimer’s Australia, 2012e; Dean, 2011a; Mackenzie, 2006a; Phillipson, Magee, Jones, & Skladzien, 2011; Werner, Mittelman, Goldstein, & Heinik, 2012), but very little on the stigma as experienced directly by people with dementia. No longer can this expertise be ignored as people with dementia are the experts through the lived experience, and not including them in research not only further stigmatizes them, but hinders the validity of the research. This is important as much of the published research is biased through the use of family carers as the main cohort group, or having them in attendance when people with dementia are interviewed, and so the carer voice remains the main voice in the dementia and stigma literature.

There is a significant body of evidence to draw upon when reviewing stigma and language, and the literature appears to show more positive attitudes. However, this may be a socially acceptable veneer covering up the embedded and unconscious negative attitudes that drive human behaviour, expressed as stigma and discrimination. It is from this position, and my personal experience of stigma and discrimination since acquiring the various disabilities of dementia, that I write this editorial. In Chapter 7: We live until we die, in *Learning Life from Illness Stories*, I wrote (Swaffer, 2012) ‘I believe there is a sense of what Martin Luther King described as “the degenerating sense of nobodiness” amongst many disabled people, especially those who are struggling with mental, terminal or chronic illness, old age and dementia’.

It is therefore imperative that we aspire to change views of and about people with dementia, and begin to include them in the research and conversations about them. Clasper (2014) writes a blog about living with dementia, and said: ‘...we wish to raise awareness of dementia, is that we all live on hope, that we can in our own little way go a long way to remove the stigma which we hear of every day in dementia’. People with dementia are raising their voices all around the world, as they want to be part of the conversations and research, and until they are included, the stigma will continue. Evidence of this are groups such as The Scottish Dementia Working Group (2002), the European Dementia Working Group (2014) and the Australian Dementia Advisory Committee (2014a), the first groups globally for people with dementia where membership is exclusive to them, and they are supported by their respective Alzheimer’s Societies. They
all advocate for a review of the language being used about them, for inclusion, reducing stigma, increasing education and awareness as the way forward in reducing stigma, and this activism is starting to be noticed (Bartlett, 2014).

**Language**

As far back as 2009, Alzheimer’s Australia said in their Dementia Friendly Language Position Paper 4:

Language is a powerful tool. The words we use can strongly influence how others treat or view people with dementia. For example referring to people with dementia as ‘sufferers’ or as ‘victims’ implies that they are helpless. This not only strips people of their dignity and self-esteem, it reinforces inaccurate stereotypes and heightens the fear and stigma surrounding dementia.

Language is a powerful tool (Anon, 2010; Cayton, 2006; Hoffert, 2006; Parker, 2001; Sabat, 2001), and our words do reflect our thoughts and feelings, and can show respect or disrespect. The words we use not only strongly influence how others treat or view people with dementia, perhaps more importantly they can impact how they view themselves and how they relate to others, which can negatively impact their ability to be empowered. It has the potential to promote and empower, enable and increase self-esteem, and encourage one’s ability to self-help, or it can demean, devalue, disrespect and offend those we refer to. People can live well with dementia, and the language used about them needs to be normal, inclusive, jargon-free, non-elitist, clear, straight-forward, non-judgmental, and which centres on the person not the disease or social care system, or language trends that come and go.

The current language used in the literature, the media and in the community creates the wrong descriptions and prescriptions of persons living with the symptoms of dementia, and creates and supports broader stigmas and misconceptions of what living with dementia is really like. It also destroys the value of the expression of the lived experience, adding to the disbelief and stigma. Hughes, Louw, and Sabat (2006) state: ‘Language creates the particularly human kind of rapport, of being together, that we are in a conversation together’. Therefore, it is imperative that we use inclusive non-offensive language that supports the whole person positively, rather than negative demeaning language that stigmatizes and separates us.

During the 2014 Alzheimer’s Disease International conference, ‘Dementia: Working Together for a Global Solution’, the language being used by the majority of the researchers and other presenters to refer to people with dementia was derogatory, stigmatizing and discriminatory. At this conference, people with dementia were publicly referred to with disrespectful, offensive, dehumanizing and devaluing language, such as ‘demented’ ‘sufferers’, ‘subjects’, ‘victims’, and ‘not all there’.

Whilst, we may have changed, we are all there. Whilst we may in fact suffer, many of us are not sufferers, and find that term offensive. We no longer refer to people with physical or intellectual disabilities as retarded or as retards, as it is offensive to them, even though technically they [we] are retarded. I place myself in the disabled category, as I have many disabilities caused by the type of dementia I have. Technically, people with dementia are ‘demented’ too; however, most of us find that and other terms offensive, and have a right to stand up and speak out about it. It is no longer appropriate for this language to be the norm;
an article by Sandblom (2014), one of the co-founders of Dementia Alliance International said:

We are just changing in ways the rest of you aren’t, we have increasing disabilities and the sooner it is looked at that way instead of the stigmas, misunderstandings and complete lies, the better for all of us living with dementia. We desperately need others to enable us, not further disable us!

There have been language guidelines for many years (Alzheimer’s Australia, 2009; Alzheimer’s Society Canada, 2012; Alzheimer’s Society of Ireland, 2008), and yet researchers, service providers and the media refuse to comply with them. Print and other media virtually insist on continuing to use outdated and disempowering negative language, preferring to refer to people with dementia as demented and suffering, as these sad-sack stories are more likely to promote viewers or readers to engage. Many refuse to consider, or use the international language guidelines for dementia, and yet never use the word retarded anymore. Unfortunately, governments like to use this disempowering and offensive language, and the Alzheimer’s Associations and societies do little to prevent it, most likely because the likelihood of governments or philanthropists providing or increasing research funding, for people who appear to be living well, would be challenging.

The Honourable Kelly Vincent MP based in Adelaide South Australia launched the C-Word campaign (C=communication) which is targeted towards people with disabilities, but she believes that the same principles should be applied to people with dementia. In an interview for DPS News (2014), Ms Vincent said ‘The way we ‘label’ or talk about clients can say a lot about what we think about them’, and went on to ‘...have the respect to check in with their clients about how they like to be communicated with’. This is important in respect to the language used in research as if something simple like language is disrespectful to people with dementia, it is also stigmatizing; this may mean researchers are biased and also discriminatory towards people with dementia, which holds them back from including them in research. It is easy to say they are a vulnerable group, they are losing capacity and so on, but without people with dementia, it is not really possible to assess things from their perspective, either anecdotally or through evidence-based research.

**Dementia friendly**

The determination by governments and Alzheimer’s societies and organizations around the world to promote dementia friendly communities and dementia champions still mostly supports the ‘about them, with them’ position, which has the potential to further stigmatize people with dementia. To date, only a few people with dementia have been included in the discussions, planning and decisions about what makes a community or organization dementia friendly. For example, disclosed during a presentation by an international expert on dementia-friendly communities (Alzheimer’s Australia, 2014b), in 10 or more years of working towards dementia-friendly communities in the UK, approximately 350 people with dementia had been directly engaged in the work; considering the size of the cohort and time frame, that is an unacceptably low number.

Furthermore, the literature does not read as dementia friendly; it is still mostly about people with dementia, without them, and the language used is still inaccurate and offensive, and not in line with the current international guidelines. Dementia is not a mental illness (Ticehurst, 2001), and as stated by Mukadam and Livingston (2012) in their article ‘We’re
still the same people: developing a mass media campaign to raise awareness and challenge the stigma, it is a pathological or neurological illness. Second, the language being used remains stigmatizing, negative and disempowering (Devlin et al., 2007). These points are worthy of further consideration, as if the research literature aiming to support decreasing stigma is not accurate, and yet gets through the peer review process, using inappropriate, stigmatizing and disempowering language, there seems little hope for progress or change.

In the World Alzheimer’s Report 2012: Overcoming the stigma of dementia (Batsch et al., 2012, p. 23), out of the 2068 UK respondents to their survey, 83% were carers and only 6% were people living with a diagnosis of dementia, and in Spain there were only 3% people with dementia versus 77% carers. The voice of others about and over people with dementia continues, and if the peak international body advocating for people with dementia is not able access a better cohort of people with dementia, it not only highlights the challenges for researchers, it continues to stigmatize people with dementia through exclusion. Of course, there are challenging ethical and methodological considerations with working with people with dementia, with other issues such as capacity to give consent, which may also change during the course of the research, their vulnerability and the possible emotional toll of participating in research (Pesonen, Remes, & Isola, 2011). It is no longer acceptable to do research about children, the disabled or the gay community, without them; it is disturbing that it is still being done about people with dementia without them.

The objective of a dementia-friendly community is to engage people with dementia in everyday life (Crampton, Dean, & Eley, 2012), and it is obviously meritorious. But just like cancer, dementia is not a single entity and it can be expected to affect any of a person’s functions such as memory, language or understanding of space. A diagnosis of dementia exacerbates issues such as social inequality, stigma, isolation, loss of identity and discrimination. It also has the potential to set the person with dementia up to become a victim or ‘sufferer’, and their family care givers to become martyrs. It has significant negative emotional, financial and social cost and impact on the person with dementia, their families and society. It disempowers, devalues, demeans and lowers self-esteem and very negatively impacts well-being and Quality of life. Engaging people with dementia, in the dementia-friendly projects, and providing dementia-friendly communities means people with dementia would become empowered to live their pre-diagnosis lives for as long as possible, and supported and enabled allowing them to ignore the Prescribed Disengagement™ given to them at diagnosis.

I have been uncertain that ‘dementia-friendly communities’ is the right phrase as I am worried it encourages division rather than includes people. Therefore, it is very important for the Alzheimer’s societies and associations to ensure the dementia-friendly community projects and initiatives work for people with dementia, and not simply encouraging a tokenistic inclusion of people with dementia. Alzheimer’s Australia (2014d) are working hard on dementia-friendly communities, some including audits on whether a community or organization is dementia friendly done by people with dementia. However, in supporting the dementia-friendly mantra, every Alzheimer’s Society or Association must themselves be dementia friendly, audited by people with dementia, and not themselves or carers. These audits, and the authentic voice of people with dementia deciding what is and what is not dementia friendly, are the missing pieces of the Dementia-friendly community puzzle, and I believe, without them, no one town, village, city, organization, region, or country can claim to be dementia-friendly.
Conclusion

In conclusion, there are a range of issues important to understand and the critical part missing in research about dementia, and the organizations supporting people with dementia, is the authentic voice of people with dementia. Stigma is endemic in the literature, and the stigma and discrimination that still exist within the organizations advocating for people with dementia are increased by the language being used about them. It is clear from my lived experience, advocacy work and research that stigma is still prevalent in the community, and amongst researchers, health care professionals and the associations advocating for and supporting us. The use of dehumanizing language and the miniscule proportions of people with dementia in the research cohorts exacerbates stigma, and potentially means that no community can be dementia-friendly. Contributing significantly to the stigma is the very low numbers of people with dementia in the conversations by the Alzheimer’s organizations about them, on important topics such as the dementia-friendly projects and stigma.

If people with dementia only get ‘used’ for fundraising, or marketing or media opportunities, little will change. This type of ‘inclusion’ is tokenistic and patronizing. The worth of any sector or agency (e.g. Universities, Alzheimer’s Society’s, Service Providers or community) purporting to support this marginalized and stigmatized group, and the value of the research or projects being done about them without them, is flawed without the full inclusion of, and the authentic voice of people with dementia. It is important to remember that dementia is a social issue and not just a medical one, and as such requires more than a medical model of care and support. There is much work to be done to assist the general public to understand and not be afraid of people with dementia, and to stop researchers and service providers from stigmatizing and discriminating against us. In short, social action is needed to ensure that we engage people with dementia, not just the wider community in understanding dementia and in that way reduce the social isolation, discrimination and stigma that people with dementia experience. We want to access services and to participate in the community the way everyone has a right to expect, and to have our disabilities respected with acceptance, support and enablement.

References


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