

The power of language

Posted on February 6, 2015 by AJDC Team • 3 Comments

Changing the disrespectful and disempowering language often used to refer to people with dementia will help remove discrimination, stigma and isolation, writes Kate Swaffer.

Language is powerful and important in discussions around providing person-centred care to people with dementia in a way that shows respect and dignity for the person. I often feel there is a very thin line between people with dementia being treated with dignity and being treated like morons, and I firmly believe nothing will change until we recognise it is imperative we all understand the human cost of dementia.

The time is now that people with dementia all over the world are standing up and speaking out about what is and isn't best for them, and this includes the language being used to refer to them. It is not a phenomenon, it is a basic human right, and as someone who is living with dementia, I have been advocating for a more respectful, empowering positive language for some time.

THE LANGUAGE OF DEMENTIA

The language of dementia is changing or evolving into one that is more acceptable to people with dementia. It may well be the key to a more person-centred approach to care and the key to reducing shame and stigma.

Until recently, the language of dementia has been decided by people without dementia. Not just family carers, but care providers, nurses and doctors, the media, researchers and academics. Now people with dementia are speaking up and saying if it is acceptable. For the most part, it is not.

After four years of being told by people in the media that I had no right to be offended by terms such as 'sufferer', since September last year I have had five journalists (yes, so far only five) agree I do have a right to be offended, that they do have a responsibility to be respectful on our terms, not theirs, and who have changed their words as a result.

The current language being used by researchers, governments, the media, the acute hospital sector and in dementia and aged care is not aligned with language standards set by consumers as far back as 2008 (Alzheimer's Ireland)

and updated during the last Dementia Awareness Month by Alzheimer's Australia (2014) as part of its Dementia Friendly Communities resources.

Stigma towards people with dementia is a salient feature of their lived experience and language contributes significantly to this. The stigmatising, negative and disempowering language used in research about the very group researchers aim to improve outcomes for is not only disrespectful to people with dementia, but may prevent the timely translation of good research into better practice.

REINFORCING STEREOTYPES

Our words do reflect our thoughts and feelings and can show respect or disrespect, and language is a powerful tool (Sabat 2009, Hughes et al 2006). 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 'victims' implies that they are helpless, and this not only strips people of their dignity and self-esteem, it reinforces inaccurate stereotypes and heightens the fear and stigma surrounding dementia.

Society listened to other groups asking for the language used to refer to them to change to one they found more respectful. People with disabilities quite reasonably expect not to be referred to as 'retards' or 'cripples', our gay community no longer accepts offensive, disrespectful or disempowering words about them and our Indigenous communities similarly have the same expectation and right to the use of empowering and respectful language, and one they have chosen, or at least been involved in advocating for.

The word dementia comes from the Latin meaning madness, so it is no wonder we struggle against the myths. Recently a State politician justified calling me "demented", because, she said, technically I am! Although I told her I find that term very offensive, she stated she had a right to use it, and I was being overly pedantic, although I doubt if she would call an Indigenous Australian a 'black' or 'nigger'.

The Google Online Dictionary defines dementia as "a chronic or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders, personality changes and impaired reasoning". The synonyms listed are: mental illness, madness, insanity, derangement, lunacy, demented, dement, senile dementia, Alzheimer's, Alzheimer's disease.

In contrast to dementia, disabled is defined as “(persons) having a physical or mental condition that limits their movements, senses, or activities”, and the synonyms listed are: having a disability, wheelchair-using, paralysed. Two years ago many of the following words were listed as synonyms for the word disability, but are now listed as words which are offensive and no longer appropriate to use: retard, retarded, tard, handicapped, impaired, crip, cripple, lame. I have this hope for the definition of dementia.

LANGUAGE AND STIGMA

Language is important. It not only defines how people see us but ultimately how we view ourselves. It allows us to communicate with others, and can impact stigma and discrimination. It has the potential to promote and empower, enable and increase self-esteem, and encourage one's ability to self-help and self-advocate. Or it can demean, devalue, disrespect and offend those we refer to.

The definition of stigma and the role it plays in defining the experience of people with dementia is well documented. In 1963 Erving Goffman referred to stigma as “spoiled identity”, and in 2001 Link and Phelan discussed it in terms of people being negatively labelled, a loss of status and power, discrimination and stereotyping.

Language affects the experience of stigma. The phrase ‘sticks and stones may break my bones but words will never hurt me’, in my experience of living with dementia, is wrong. They do hurt me and offensive and demeaning labels and language simply intensifies the shame and stigma people with dementia already feel.

Stigma affects a number of things, including the person's willingness to seek diagnosis, to seek support once diagnosed, and a lack of willingness to participate in research. The care provided is also of a lower standard due to passive stigma within the health care profession, and services appear distorted. Scheff (1990) claimed stigma increased the feelings of shame, and in 2012 ADI (Batsch et al 2012) reported people with dementia still feel a deep sense of shame. This is unacceptable, and I believe language has a lot to do with it. Stigma affects more than just well-being and quality of life for people with dementia and their families, and negative, disempowering and disrespectful language increases stigma.

Stigma is still a salient feature of the experience of people with dementia. Because of this, earlier in 2014 I explored the existence of stigma within the dementia literature, looking at it in a new way by questioning whether the researchers exacerbate stigma, even though their intent is to promote positive change. It is apparent there is a lack of research focused on the effect or feeling of stigma from the perspective of the person with dementia, and how stigma might be exacerbated by the use of incorrect information and inappropriate and offensive language used to describe people with dementia.

Considering the lack of inclusion of people with dementia in the cohorts being studied, it is still very much "about them, without them", which cannot give a true picture of the issues at hand for this particular group, and simply reinforces the stigma.

Caregiver stigma has been explored often (Werner et al 2012; Mackenzie 2006; Dean 2011), 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. Not including them in research not only stigmatises them, but it 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 present when people with dementia are interviewed, and so the carer voice remains the main voice in the stigma research.

There is a significant body of evidence to draw upon, and the literature appears to show more positive attitudes towards people with dementia. 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.

Language, inclusion and providing dementia-friendly communities are important in reducing stigma, and without positive change, stigma will continue to be a significant burden on people with dementia.

LEARNING A NEW LANGUAGE

South Australian MP Kelly Vincent says when communicating with people with disabilities, they are the experts; so too are those people diagnosed with dementia.

We would not hesitate to consider the communication needs of a child or a person with a speech disability and yet this is frequently not the case for people with dementia. Karen Fossum wrote: "When your child is no longer a child, you will have to find a new language" (2003). That is not to say people with dementia wish to be spoken to like children, but rather that the same amount of effort and respect is placed on learning to communicate with us as our needs change.

This surely applies to how health care staff deliver care to people with dementia, as our impairments should require that staff know how to assist with these impairments. Unfortunately, I have more often seen impairments regarded as 'difficult behaviours', which are then treated with restraint of some kind, rather than being seen as impairments to the person's ability to communicate. I find it curious that speech pathologists are not included in the care plans of people with dementia, considering our language and speech impairments, and their expertise in this area.

Let's hope also that those caring for people with dementia will consider the impairments we have in language, literacy and numeracy and assist us with better strategies to manage them, rather than 'treat' us with drugs or other forms of restraint or insults. It might appear funny not knowing how to use a biro, but the frustration of not being able to do a simple task like that is very annoying! I know, and although most times I still know how to use a biro, many other simple tasks have become difficult, or impossible. Of course we will display 'challenging behaviours' if no-one bothers to understand our frustrations, or our needs.

When people with dementia have reduced or impaired language abilities it is up to others to learn how to communicate with them, not the other way around. If challenging behaviours become part of the experience, it is more likely due to the person not being able to express things like pain, dissatisfaction with poor-tasting food or being bored, than it is the fault of the person's dementia.

If we continue to behave in challenging ways, then others need to change something, not us. Using physical or chemical restraint is not the answer, but rather a blatant abuse of our human right to be understood and cared for in the best way possible.

It is also a human right for people with dementia, many of whom have speech impairments and language difficulties, to expect the provision of speech pathologists to provide care and assistance to maintain language for as long

as possible. So far, this allied health specialist is missing in action in the dementia sector, and I have never seen or heard of one being employed to assist people with dementia, other than the one I use, engaged privately.

WHY LANGUAGE MATTERS

Language matters. Consider the phrase 'suffering from' dementia vs 'diagnosed with' dementia. The first one is negative and disempowering. 'Demented' or 'a vacant dement' as I read recently, are no longer acceptable terms for people with dementia. First and foremost, we are people, with names, living with dementia.

The term 'living with dementia' is now only appropriate to use for the person diagnosed with dementia, the very people it affects more deeply. This is not to say our beloved carers should not be part of the conversation. It is obvious they are, and we quite rightly must respect them and their opinions. We love them and appreciate their care and support, and in no way would we wish to insult or offend them. However, they are not living with dementia. Only those diagnosed are living with dementia, in the same way my husband would not say he is living with arthritis or cancer if I was diagnosed with either of those conditions.

When talking about language and difference, language and how it makes us think about people and act towards them has a practical impact on the way our community treats those of us we see as being different. In the past and still now, much of the language used to refer to people with disability or impairment and life-limiting disease has been developed by others, such as researchers or clinicians.

It can be argued that this medicalised approach has led to most of us thinking about the impairment or disease – the condition – before the person and this may well be one of the barriers to the provision of person-centred care. It's my belief that this approach leads to a sense of treating people as 'other', or 'us and them'.

You can argue that this is at the heart of discrimination and helps create a sense, or reality, of fractured community. A more recent move has been to try to see the person first and then the condition, but negative disrespectful language can hold this back.



This t-shirt logo,

designed for Dementia Alliance International, speaks volumes

SPEAKING UP

We are all part of a contiguous community, we all live here, we are all people and we all need to consider each other as people – not cases, subjects or conditions. In today's thinking, those of us who belong to an identifiable group have advocated for the right, capacity, ability, 'permission' to identify ourselves, speak for ourselves and promote the language that is used about us.

While no individual in any identifiable group can be said to be the single voice of that group, it is the right of that group as a community to have a voice to speak about how it is that the 'rest of us' speak about them – therein lies empowerment.

Changing the current disrespectful and disempowering language will help to remove the discrimination, stigma and isolation, and will help others see that people with dementia are still very capable of contributing positively. As we have not been active in our own advocacy until recently it is not yet the norm, and this affects how people treat us.

It is a very recent phenomenon that people with dementia are included in the conversations about them. Sadly, staying engaged means many people with dementia are accused of lying about their diagnosis. Personally I prefer to ignore these doubters and continue to strive to live well with dementia; it comes from the stigma still very present, and from the myths and ignorance that still exist in the community and the health and dementia care sectors.

It is clear from the numbers of people with dementia who are standing up and speaking out as advocates that there is still a good life to live even after a diagnosis of dementia. We do not have to accept the Prescribed Disengagement™ and give up our pre-diagnosis lives. As I wrote in the last issue of AJDC (December 2014/January 2015), I recommend to everyone who has been diagnosed with dementia to ignore this well-meaning but negative advice (Prescribed Disengagement™) and re-invest in life.

QUESTIONING BPSD

Finally, I remain extremely sceptical about the use of the category Behavioural and Psychological Symptoms of Dementia (BPSD) and believe the categorisation of behaviours into things like 'wandering', 'aggressive', 'absconder', 'screamer', 'poor feeders', and so on, simply increases the likelihood of person-centred care not being delivered, and increases issues such as shame and stigma.

The official category BPSD was the result of a consensus conference organised by the International Psychogeriatric Association in the US in 1996, which interestingly, was sponsored by Janssen Pharmaceuticals. It had a major impact on research, intervention and definition of dementia. In terms of interventions, previously existing drugs, like the cognitive enhancers, began to be tested for non-cognitive outcomes such as activities of daily living, behaviour, and global outcome (Leibig 2014).

It appears from this article that the term BPSD has been developed by pharmaceutical companies, and my cynical consumer/student perspective suggests to me it was simply a way to define people with dementia in ways that can be managed by drugs, for example anti-anxiety or anti-agitation medications. People with dementia have been labelled disparagingly to allow the prescribing of 'behaviour' modifying drugs, simply because of a failure of the pharmaceutical industry to find enough dementia (disease) modifying drugs and the lack of a cure.

People can live well with dementia and the language used about them needs to be normal, inclusive, jargon-free, non-elitist, clear, straightforward, non-judgmental and centre on the person, not the disease or social care system, or language trends that come and go.

CONCLUSION

It is absolutely the time for governments, the media, the health care sector, researchers and the community to reconsider the way they refer to us and speak about us, and to listen to our request for something as simple as language that people with dementia agree is respectful.

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