

# A Report Discussing How Awareness Can Be Used To Reduce the Stigma of Dementia and Help People to Live Well With the Disease



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## Introduction

The aim of this report is to explore the need for increased awareness of dementia and how this can assist a person with dementia to live well, through reducing the stigma of the disease. In a survey of people with dementia [1], half of all the participants stated that they believe there was a stigma to the disease, and in addition to that it was the second most feared condition, second only to cancer (Survey on stigma levels sparks call for campaign [1]). These results show that the stigma of dementia is very prevalent and needs addressing as a matter of urgency.

According to Devlin et al [2] it is these stigmas that is important to identity and therefore tackle to help make the lives of people with mental incapacity truly better. Dementia has also a considerable amount of misunderstanding and fear, It is stated that misunderstanding and stereotypes helps to create the fear and stigma as there are very negative connotations within the disease, and there is a belief that 'nothing can be done'[2]. This shows that as well as reducing the stigma of society, a person with dementia's own perceptions of the disease is important to address it discusses the need for greater understanding in people with dementia, especially in diagnosis; many people do not peruse a diagnosis through the belief that there is no benefit of being diagnosed as there is not current cure. This demonstrates the importance of increased awareness, especially in the attainment of a diagnosis; where greater awareness would reduce the fear of dementia and therefore assist in gaining the diagnosis needed and the improve the access to the services needed to help the person with dementia to 'live well'.

Stigma within society is important to address as it can create social isolation with people living with dementia Batsch and Mittelman [3]. Social isolation is created by the fear of dementia from the person living with it and society. Social isolation within dementia is important as it helps a person to feel part of the community and therefore live independently Alzheimer's

Society [4]. According to The communities have a part to play in supporting people with dementia to live independently, this therefore demonstrates that awareness of dementia needs to be reduced to assist in supporting people with dementia, and consequently breaking down the stigma and fear of the disease.

Knowledge is a large barrier in dementia care especially through the misunderstanding that the disease is a normal part of ageing Brown [5]. The view that it is a normal part of ageing has many implications in particular younger people with dementia. Due to the lower prevalence of people with early onset dementia they are commonly not taken seriously by professionals and therefore diagnosis is not easily attained. A separate stigma and form of oppression is evident with people with early onset dementia, due to the lack of awareness, there is a serious lack of services and support which in turn creates the feeling of isolation with people living with early onset dementia Chaston [6]. As well as professionals not being aware of early onset dementia, society is very sceptical and it is not common for people to be told that they are too young to have dementia, this demonstrates that there is the need to gain more knowledge and understanding to help support people with early onset dementia which in turn will reduce the stigma and fear of the disease by being more inclusive within society.

Another important point to consider is that greater awareness needs to be achieved to asset the feeling of personhood in dementia. This idea of personhood is important as it allows a person to look past the negative stigma of the disease and treat the person as an individual. The theory of personhood is very prevalent within the teaching of Kitwood and person-centred care Kitwood's person centred theory looks at an equation that assists in understanding the person not the disease Maciejewski [7]. Kitwood's equation consists of: Personality, Biography + Health + Neuropathological Impairment + Social Psychology,

once these are all discovered Kitwood states that you then learn who the person with dementia truly is. The equation fits in with the reduction of stigma through social psychology. According to malignant social psychology is not necessarily malicious but normally evident where people struggle to care, this fits in with the stigma of dementia as it is the lack of awareness and understanding that causes the negativity towards the disease.

The lack of awareness of dementia in other cultures is an inserting point to consider when discussing stigma within dementia. According to Jutlla [8] there is a lack of work in understanding the importance of different cultures and their norms. This demonstrates that there is a need for more awareness within different cultures as through the lack of knowledge and understanding, oppression and ultimately a form of stigma may occur within this specific group of people also states the importance of involving the person's culture and life histories in their care, this relates to Kitwood's work of personhood as previously discussed earlier in the assignment, Kitwood states you need to know more about the person not just the disease. The knowledge of a person's culture will help in care giving and reducing the stigma through gaining knowledge of the understanding shown by the specific culture and thus helping them to understand the disease Jutlla [8].

### Methods of Raising Awareness and Policies

There are many methods for raising awareness of dementia and therefore tackling the need for the stigma of the disease to be reduced. The many different methods of raising awareness can be national regional or at local level. Terry Pratchett sums up what is required to reduce the stigma, he states that everyone needs to work together to educate the people around us as well as allowing people with dementia to have their voice Hunt [9]. This view therefore shows that awareness and understanding is key to reducing the stigma of dementia and therefore helping people with dementia to live well with the condition. The main methods used within the UK are Awareness campaigns, an example of a national awareness campaign that has been brought about as part of the Prime Ministers Challenge in the UK is the Dementia Friends Initiative.

The Dementia Friends Initiative is a Department of Health funded drive that is led by the Alzheimer's society, the initiative give free information sessions to the general public and look to create greater awareness of the disease Department of Health [10]. According to the aims of the gained knowledge from the information sessions is to help people to challenge the way they act and think about dementia and reflect on how they can support people with dementia, therefore making them feel included within their community. The Dementia Friends Initiative aim's to make one million Dementia Friend's by 2015. This initiative shows a way that national campaigns can be used to generate awareness and there for help break down the stigma of the disease through supporting people with dementia

and helping stay part of the community. A possible weakness of this initiative is that there is a possible lack of involvement of people living with dementia, According to Batsch and Mittelman [3] it is important for the needs of people with dementia not to be overlooked in campaigns and the best way to ensure you are meeting their needs is to involve them in the process.

Local awareness campaigns are also important in raising awareness of dementia as they help to reduce the isolation of people with dementia in their local community. In January 2014 a local awareness campaign in Edinburgh was launched to help the public to recognise the signs and symptoms of dementia, The aim of the campaign was to adhere to the long term plan to make Edinburgh a dementia friendly city. According to Transform Edinburgh [11] the campaign is set out to help with the associated fear and stigma of obtaining a diagnosis, its aims to increase awareness and therefore reduce fear, which is hoped, will increase the diagnosis rate in Edinburgh. This local campaign shows that awareness is a top priority but as with the Dementia Friends Initiative is important to make sure that it is meeting the needs of the people with dementia and not just about meeting targets.

The Prime Ministers Challenge is an important incentive developed and led by the UK government. The Prime Ministers challenge pledges three main key commitments: Driving improvements in health care, creating dementia friendly communities that understand how to help and Better research (Department of Health [12]. The key theme that is most relevant to the need to reduce stigma is the 'creating dementia friendly communities that understand how to help' commitment. Under this commitment the challenge pledges to create dementia friendly communities, attain support from leading businesses, increase public understanding and generate a nationwide awareness-raising campaign. It is apparent that the Dementia Friends Initiative is the Campaign in question and through the creation of dementia friendly communities local campaigns are supported from central government. The Prime Ministers Challenge looks to address the needs of people with dementia especially in creating awareness and reducing the stigma and fear of the disease, it does this by pledging many commitments that support the methods of raising awareness. A weakness of the Challenge is that it is very conservative, an example is that it plans to make 20 towns and cities dementia friendly Department of Health [12]., this is a very low number in regards to the size of the UK and it gives the impression that the awareness will not be consistent though only a small number being part of the challenge.

### Importance Media Plays in Creating Stigma

As well as generally looking at how awareness can reduce the fear and stigma of dementia this assignment will look at how media can play a part in assisting with awareness; but also being detrimental to people view of the disease through negative

connotations. Media is important in dementia awareness as it is one of the more common sources for the dissemination of information of dementia within the public domain Kirkman [13]. This emphasises the importance of media in raising awareness as it could be utilised in a very powerful awareness raising tool that reaches many. The sad fact is that many of the media outlets are not very positive about dementia and this will be evident within the assignment where a news article will be critically analysed to see the standard of current media focusing on dementia.

The media is very commonly very negative about dementia through using negative stories and accounts of dementia Doyle [14]. According to negative stories especially within residential care are the most common form of media attention towards dementia, these stories create fear of the experiences people have with dementia and therefore re enforce the stigma of the disease. It is important to note that even through the cases of neglect being small, due to the media reporting on it the view of residential care is negatively affected, It is important to look at the impact on relatives and society, through the negative stories the stigma of the disease is prevalent as relatives and people with dementia may believe that this will happen to them, therefore creating fear.

According to positive language within media can increase awareness of the condition while reducing the fear and stigma of dementia, In it demonstrates that media is not very positive and therefore it creates the fear and stigma that positive language could tackle. It is interesting to note that media can go too far with attempting to reduce negativity as in it states that some media have trivialised dementia, this shows that if not conducted sensitively, the media can be perceived as not taken the condition seriously and therefore demeaning the person with dementia. As mentioned earlier the lack of awareness and understanding can lead to the loss of the person and therefore the focus becoming solely on the disease, this is common in the media as Alzheimer's and other dementias being portrayed as especially cruel diseases therefore the emphasis is on the diseases and its effect not the person living with it Kirkman [13].

This fits in with the theory of personhood and Kitwood teachings as previously mentioned in the assignment where the importance lies in knowing the person with dementia not the disease. Another issue in Media is the lack of knowledge, for example According to many media articles make reference to dementia being an inevitable part of ageing which is untrue and therefore miss leading, this reinforces the fear of the disease within older people with dementia as well as exclude people with early onset dementia therefore strengthening the stigma associated with dementia.

An example of a negative piece of media is 'Dementia time bomb will cost the NHS millions' published by the Mail in the UK Roberts [15]. The article in question immediately is negative by calling it a 'timebomb' and by focusing on the cost. The language

is very negative throughout and focuses on the negative implications that dementia has on the NHS. The article also calls people living with dementia 'sufferers' this is very negative and gives the impression that people with dementia cannot live well. Another point is that it refers to dementia being diseases that 'occurs in the elderly' therefore it is giving the connotation that this is a part of aging or that it only occurs in older people. In contrast in 'Dementia: taking care' published in the Guardian UK, The Guardian [16] the article looks at a similar topic and does discuss the impact of dementia on the economy but this is not the main point of the article. The language used is significantly less negative and the term 'sufferer' is not used, this means that less fear around the diseases will be generated and therefore it will start to break down the stigma of the disease.

The article does mention that the disease was regarded to be a part of ageing but does not explicitly state that it is not a normal part of ageing, this shows that even though the theme of this article is positive there is still more room for improvement and work to be done with media in general.

Another way of raising awareness is social media, social media recently has had a large increase through the high number of people now accessing the internet Robbillard et al [17]. According to the reason for social media being used more frequently within this field is because anyone can raise awareness not just the experts in the field, this shows that giving more freedom to who can discuss the topic of dementia is important and successful especially in regards to social media. Social media is also a powerful tool for people with dementia to feel included; In to it states that people can interact with social media and therefore become socially supported and included within society. This demonstrates that as well as raising awareness of dementia in society social media can be used by people with dementia themselves to help to feel connected and therefore help them to 'live well'.

### Conclusion

Awareness and the reduction of the stigma of the disease is a very topical and important consideration which has become at the heart of dementia care in the UK. Through a greater understanding of dementia, the breaking down of the stigma of the disease can be easily be achieved. The majority of the time it is this lack of understanding that causes the stigma in the first place. There are many different ways of increasing awareness ranging from National campaigns such as the dementia Friend's Initiative to local campaigns such as making communities friendly. The media is also important in tacking the stigma of dementia through the reduction of the negative stories, increased knowledge and understanding and more positive language.

On a different train of thought it is important to note that even academic work can have very negative language and themes, this became evident through the literature search for this assignment

where in Robbillard et al [17] very negative language was used, this shows that if the experts are not addressing the need for more positive writing then how do we expect the media or general public to address these need? Developing even further on this point is the thinking that possible awareness could be taken to the extreme where we do not blame the individual for any inconvenience caused by dementia but the disease. This on a micro level is very positive but on a macro we end up blaming the disease more, so this could be perceived that in relation to the stigma of the disease it turns full circle and we could ask ourselves therefore does this improve the stigma of the disease at all? And whether we have to re think the relationship of awareness and reduction of stigma [18-21].

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